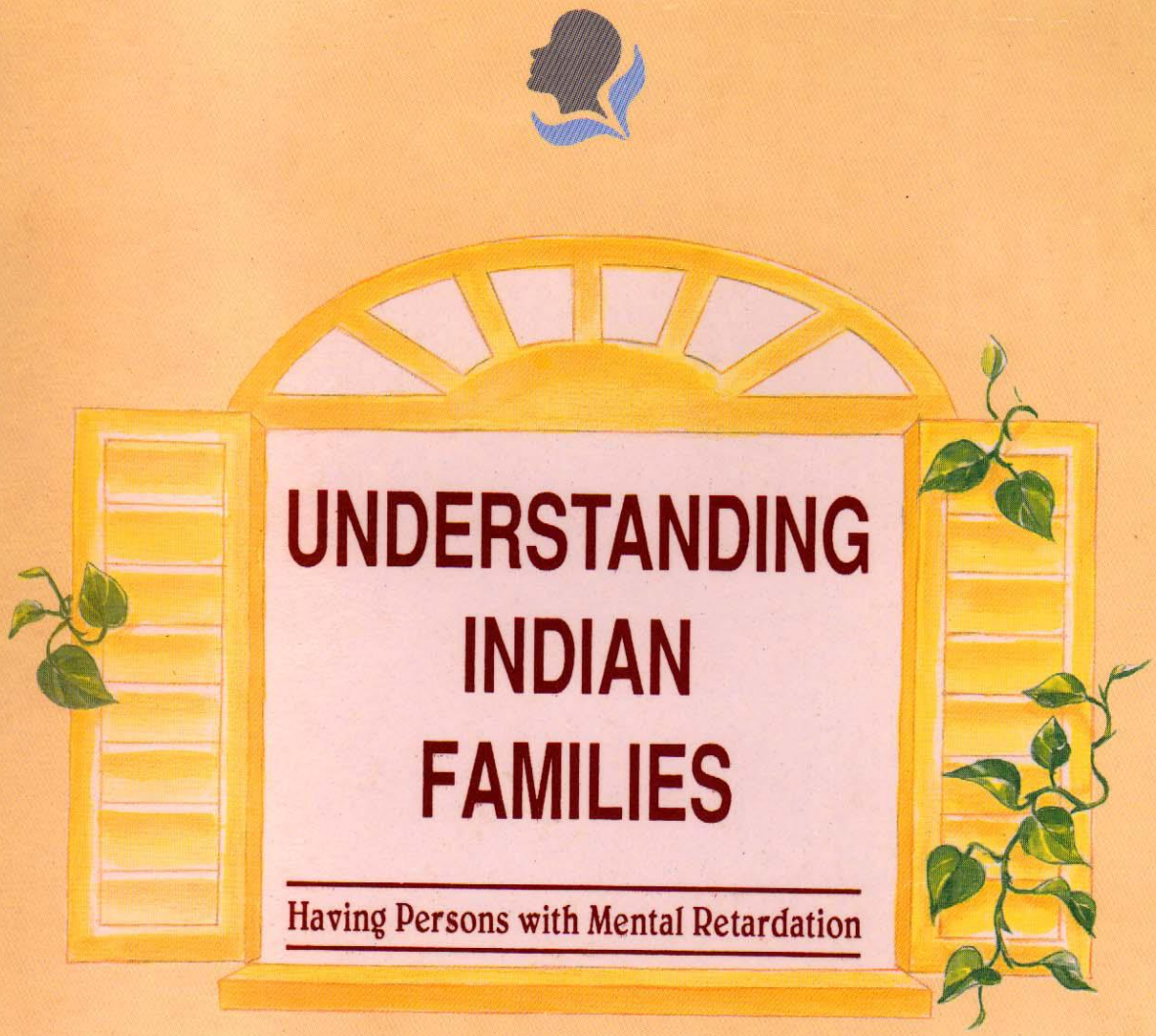
UNDERSTANDING INDIAN FAMILIES NIMH



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Having Persons with Mental Retardation

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STRENTHENING FAMILIES
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CONTENTS

FOREWORD

It gives me immense pleasure and makes me feel proud as well to pen this foreward. This book is a product of unique and unsparing efforts by eminent experts in the field of mental retardation. This book brings to light understanding of the maladies and constraints of the lives of families having mentally retarded individuals. This book is a befitting contribution especially at a time when the world celebrated the year 1994 as "International Year of the Families".

This book based on empirical research shares valuable data on various aspects of the families such as impact on families having individuals with mental retardation, their needs, supports and coping. For the first time emphasis has been laid to understand all the members of the family that is, mothers, fathers, sisters, brothers, grandmothers and grandfathers.

This book offers potential material to positively assist and influence the parents and other family members in the process of normalisation and effective coping. The book provides direction to fill the gaps existing in service provision especially to meet the specific identified needs of the families. Also, it has provided good direction for future research in the area. The authors have developed a "Family Needs Schedule" which will help professionals in designing and conducting need based services. Conceiving and presenting a "Need based family intervention model" should definitely stimulate the service providers.

This compilation, I dare say is the first milestone in documenting social situations hitherto unexplored in the areas of social process involving members of the famiies of the handicapped persons. As a fore-runner, it lays down not only the foundation, but also will serve as a beacon to help further work in this field. Therefore, this book amounts to a very unique and important contribution to the field of disability and rehabilitation and to our society.

The subject matter is dealt with directness and indepthness, therefore, I am sure, we will find this book placed in libraries and homes alike.

I close this foreword with a personal wish for this book to reach all, for whom it is intended, as it is certain to bring awareness amongst the professionals, parents and society at large.

Gita Shah

Dr. GITA SHAH
HEAD DEPT. OF EMS,
TISS, BOMBAY

Date: June 26, 1995.

PREFACE

The institution of family is considered essential for the existence of society. Family serves as a shock absorber in times of crisis and stress. On the other hand family itself can precipitate conflicts and generate stress amongst the family members. Having a child with disability in a family is not the same as having a child without a disability. Presence of a mentally retarded person in a family is known to impact families in varied ways generating special needs not only for the mentally retarded person perse but also for the different members of the special family including mother, father, brother, sister and grandparents.

Prevalence figures point to 2% to 3% of the general population having mental retardation. Keeping the conservative figures of 4-5 members per family, it is thus estimated that 10% of the general population in India get directly affected because of having a child with mental retardation and hence have to learn to cope up with this special situation. Presently in India we are passing through a phase in the area of rehabilitation wherein efforts are being made to spread services and training programmes, to raise awareness levels related to mainstreaming, and provision of equal rights and opportunities for the mentally retarded individuals. Unfortunately not much attention has been or is being directed towards the family members having mentally retarded persons despite the fact that they are the directly affected population and also are the prime care-takers to provide life long support and security to the mentally retarded persons. The benefits of parental and family involvement in the rehabilitation programmes has never been understood better than now. Professionals are beginning to realise the benefits of family oriented approaches over merely child centered ones.

Being a strong believer that empiricism should be the basis for providing direction to services and scientific evaluation of services should be a necessary ongoing process in the light of consumer satisfaction and need fulfillment that a multi-centered project"Strengthening families" was taken up by the National Institute for the Mentally Handicapped in 1993-94 in collaboration with three voluntary organisations namely Navjyoti Centre, Delhi, Digdarshika, Bhopal and Bal Vikas Institute, Trivandrum. The book "Understanding Indian Families

having persons with mental retardation" is an outcome of this project. The other contributions brought out separately under the project include (a) Moving Forward - An information guide for parents of children with mental retardation, (b) 30 minute Video film for meeting information needs of parents "Manzil Ke Ore".

This book has been written with the following intentions:

1. To emphasise and strengthen the focus of service provision towards understanding the unique needs of Indian families having mentally retarded persons and providing need based family interventions,

2. To suggest directions for service provision based upon the empirical understanding coupled with rich experience of working with families having persons with mental retardation,

3. To share with professional colleagues the research based information on Indian families having persons with mental retardation and to stimulate further research in the area.

The tool "NIMH-Family Needs Schedule" (NIMH-FAMNS) developed for the purpose and information gathered through research on 'Families' is shared in this book under various chapters. The first chapter on **"Families: Perspectives"** provides a theoretical framework for working with families having people with disabilities. It also provides information on the presently available models of services for families in India. In the chapters (2 to 7) research findings in the areas of **Parents: Impact; Assessment of Family Needs: Development of NIMH-FAMNS; Parents: Needs, Facilitators and inhibitors in coping; Siblings impact and needs, Grandparents; support, impact and needs** are presented. Available research both Western and Indian on the given areas is reviewed in each of the chapters. Indication for service providers and some guidelines for further research are also included in each chapter. In the last chapter 8 of the book. **"Need based family intervention model"** is introduced.

It is important and healthy to aspire for having the right people at the right places for right results. To take the first few steps in this direction, chapter 8 on "Need based family intervention model" presents an outline emphasising the need to match professional competencies with required professional tasks to be performed while working with families having persons with mental retardation.

To select people who have the required skills to work with the families or to upgrade the existing staff in the needed skills through pre-service or in-service training deserves attention by the service providers, policy makers and decision takers in the field of rehabilitation.

This book is primarily meant for professionals or to-be professionals interested to constructively contribute and work with families having persons with mental retardation. However, this book could also be of use to the family members of mentally retarded persons in bringing about awareness regarding their strengths, perception of their needs as also finding ways of their need fulfillment.

Dr. REETA PESHAWARIA
PRINCIPAL INVESTIGATOR

ACKNOWLEDGMENTS

It is with utmost humility and gratitude that we would like to thank parents and families having mentally retarded children who helped us in understanding their concerns. But for their trust and sharing with us we would have not been able to share the information included in this book.

National Institute for the Mentally Handicapped, ventured for the first time in funding multi-centered projects as the present one, in collaboration with the non-government organisations. We express our deep appreciation and grateful thanks to Dr.D.K.Menon, Director, NIMH for encouraging initiation of research projects such as this, which aims at "Strengthening families having children with mental retardation". Also, the expert guidance, continued support and significant contributions made by him throughout the project has been most encouraging.

It has been an enriching experience sharing and working together as a team with the coordinators of the project Dr.Rajam P.R.S.Pillay, Director, Bala Vikas Institute, Trivandrum; Mrs.Asha Gupta, Director, Navjyoti Centre, Delhi and Mr.Sumit Roy, Executive Director, Digdarshika Institute of Rehabilitation and Research, Bhopal.

Mr.Rahul Ganguly, Research Officer, deserves a special mention. He has been a great asset to the project. It was a real feeling of pride to see him growing from my student to my colleague. His true and total involvement and significant contributions to the project, deserves special credit.

Mr.V.Shankar Kumar, Stenographer, NIMH provided good support in typing the script as and when required. We thank him for his contributions.

We would like to express our special thanks to Mr.B.Surya Prakasam, Bio-Statistician, NIMH for assisting in supervising the Statistical Analysis of data, and to Mr.V.Ravi Kumar, Publication Assistant, NIMH for his extended help in Desk Top Publishing work of this book.

CHAPTER 1

Families : Perspectives

INTRODUCTION

The benefits of family centered interventions are being greatly recognised now more than ever before. Efforts are being directed towards involving parents and other family members in the training and habilitation of the mentally retarded individuals precisely for the reasons that such approaches result in both positive parent, family and child outcomes. It helps in enhancing child development, reducing stress in the family, increasing family coping and also leads to improving relationships within the family. For strengthening the families having mentally retarded children the interventions need to be directed both towards meeting the needs of the index child, of parents, siblings and extended family members as also recognise, promote and utilise the existing strengths of the families.

MODELS IN FAMILY FUNCTIONING

Interventions with the families must be based upon a thorough understanding on the factors which effect the functioning of families having a child with disability. It is well understood that:

- Families both affect and are affected by their disabled members in various ways (Mink and Nihira 1987).

- An intervention with any member is in fact an intervention with the whole family (Berger and Foster, 1986).

- Interventions with an individual disregarding the family functioning may result in an increase in the problems experienced by the family as a whole (Chilman, Nunnally and Cox, 1988).

To understand how families having individuals with disabilities function, three main models are briefly presented.

1. Transactional model
2. Social Ecological model
3. Family systems theory model

TRANSACTIONAL MODEL

This approach acknowledges the interaction between the biological and environmental contributors to development and argues that these factors alter the impact of each other over the time. Thus, biological and environmental factors interact at time one to produce changes in each other. These changed biological and environmental factors then interact at time two, and so on. The term transactions refers to the dynamic process of change over time that can be used to explain development.

Basically this approach emphasises three aspects:

a) Development is believed to result from a continual interplay between a changing organism and a changing environment.

This indicate that the child with disability affects the family and the family environment affects the child development and behaviour. For example, a child with disability may impact the mother placing extra demands to care. To adjust with the extra care demands the mother may leave her paid job, causing financial stress, effecting other siblings and even leading to relationship problems within the family in turn affecting the child with disability.

b) As people with disabilities pass through different developmental stages they will affect their families in different ways.

People with disabilities affect their families differently while they pass through different stages of development. For example, an older member with disability will affect the family differently in comparison to a new born with disability.

c) How families affect their child with disability will depend on the particular stage in life cycle which they find themselves in.

People with disabilities get affected differently depending upon the stages of life cycle that parents go through. Such as, a child with disability born as a first child to young parents will get affected differently as compared to a last child with disability born to middle aged couple. Hence characteristics of the child, family and the ecological context in which the family interacts over time produces changes within the family.

SOCIAL ECOLOGICAL MODEL

Understanding families through the social ecology perspective was initiated by Bronfenbrenner (1977, 1979) which has been aptly applied with families having persons with disability by Mitchell (1983) and Bubolz and Whiren (1984).

- Under this model, family is seen as an integral part of a number of other existing systems in the society, see Figure 1.1 Ecological model.

- The main feature includes, that to bring change on the behaviour of an individual, change in the environments is essential.

- The child and the family can be affected due to events occurring in a given system of which he/she may not be directly involved.

The main emphasis in this model is on the influences of social environment on a given child or the family. The social ecological view further states that the individual in one system can be affected by events occurring in other systems even if he may not be directly involved or present in that situation or settings. An illustration of this phenomenon is one in which acceptance of a young child with disability may be affected by conditions of parents coping skills. Attitude of the parent's in-laws can affect the parent coping skills. The attitude of the society towards disabled persons can shape the attitude of paternal in-laws. The core of this model is the concern with progressive accommodation between a growing organism and its immediate environment and the way the relationship is mediated by forces from remote regions in the larger social and physical milieu.

The sub systems include:

a) **Micro System:** Includes the pattern of activities, roles and interpersonal relationships experienced by the family. Components include mother/father, parent/disabled child, parent/non-disabled child.

b) **Meso System:** These include wide range of settings in which the family actively participates. These include professionals, extended family, friends, work/recreation associates, other parents, community assistance/s.

c) **Exo System:** includes influences and settings in which the family is not actively involved such as mass media, health care system, social welfare and education policies.

d) **Macro System:** These include ideology or belief systems inherent in social institutions such as religions, cultural, socio-economic factors, economic and political atmosphere of the state/country.

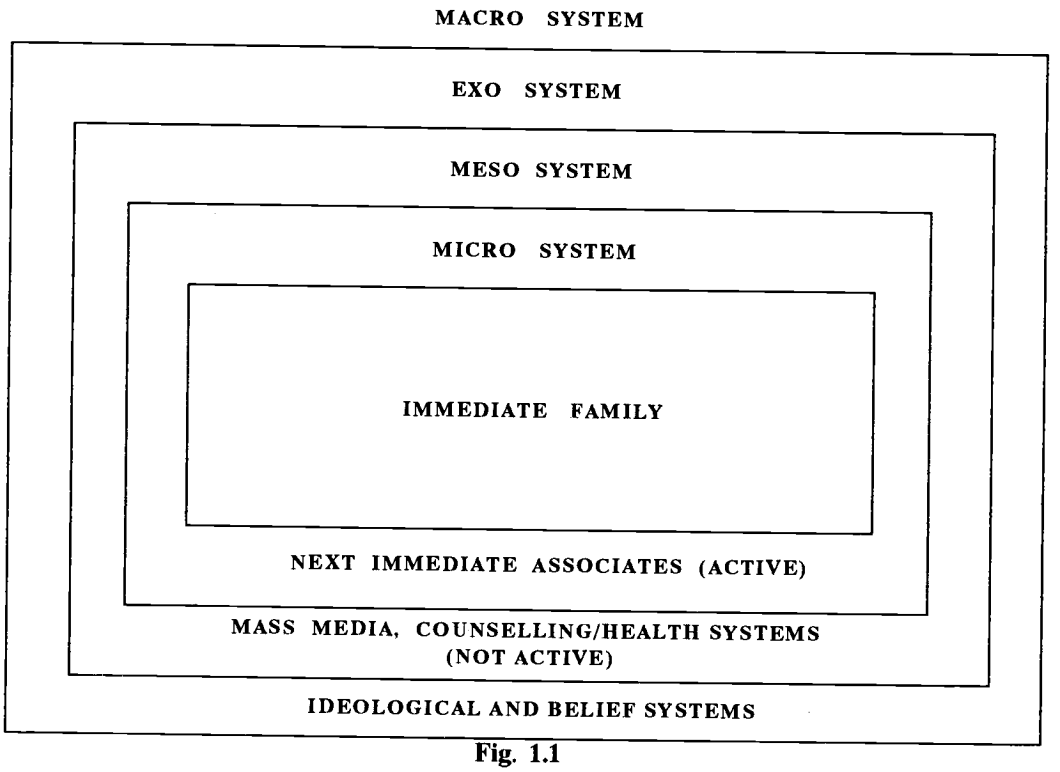


Fig. 1.1
ECOLOGICAL MODEL

FAMILY SYSTEMS THEORY

A Family Systems approach provides a comprehensive framework to understand particularly the functioning of families having children with disabilities. Originally based on the work of Von Bertlanffy (1968), its applications have been extended to families having children with disabilities by Turnbull, Summers and Brotherson (1984); Turnbull and Turnbull (1986). This model stresses that family as an institution though considered to be static because of its structural aspects yet has an ever changing and a dynamic character which is unique for each family depending upon a number of factors. These factors are clubbed under four major components including family characteristics, family interaction, family functions, and family life cycle. Understanding of these components helps appreciate how each family

turns out to be unique in meeting the challenges because of having a child with disability. Understanding families from systems perspective helps shed the stereotype that all families having children with disabilities are homogeneous forcing them all in one basket. It also provides a highly useful background understanding for planning and conduct of individualised family interventions. The components of family systems theory are briefly discussed.

a) Family Characteristics and Coping

The characteristics of each member of the family including the child with disability makes the family unique. These include type and level of severity of the child with disability, demands of the child with exceptionality and of other family members. Characteristics of the family include family size and form whether it is nuclear or extended, religious background, socio-economic status and area of residence or family having more than one member with disability. It also includes personal characteristics such as physical and mental health of the family members. How the family will influence the child with disability or the child will get effected, how well the family will adapt will much depend upon the internal coping skills of parents and other family members, the ideological and cultural beliefs and the resources of support systems available to the family from within or outside the family. For example, a family in which a parent believes that the child with disability is a result of past deeds or everything happens with God's will, if God wants only then the child can improve and that parents can do nothing to bring improvement in the child. Such cognitions and perceptions of parents will immensely influence the course of action the family takes will have repercussions on the family functioning as a whole.

b) Family Interactions

This emphasises the role of interactional patterns in family functioning. Particularly between husband-wife, parent-child, between siblings and between extended family members. Intervention in one sub-system such as mother-child can have repercussion for other sub-systems. For example: Mother spending time on training the child with disability could lead to ignoring another child which could further lead to sib-rivalry leading to

relationship problems between siblings. Hence, there is necessity to involve all the family members and provide need based family interventions. It also brings forth an understanding that families vary in the degree of cohesion, adaptation and communication. Which means that families vary in degree of emotional bonding between family members, level of independence each member has in the family and in the family's ability to cope up and change in presence of stress. Hence, the need to understand each family is crucial.

c) Family Functions

Turnbull and Turnbull (1986) lists number of functions which a typical family performs. These include: Economic, domestic/health care, recreation, socializations, self-identity, affection and meeting educational/vocational needs of the family members. It is rightfully advocated that children with disabilities should live in least restrictive environments i.e. living within a family which is least restrictive. However, managing the restrictions that these children may pose on different family members such as leisure and social restrictions, financial constraints, extra care, health risk cannot be overlooked.

d) Family life cycle

Time is a great influencer of change in every sphere. Family characteristics and its functioning also change over time. Olson et al (1984) advocated seven stages in relation to developmental changes in families. These include : couple, child bearing, school age, adolescence, launching, postparental and aging. Applying these to families having children with disabilities Turnbull and Turnbull (1986) mention the stress that these families undergo as the child with disability moves through the life cycle. During birth and early childhood the concerns are centered around discovering diagnosis, gradual awareness, assessing early childhood services, setting expectations. The childhood stage is connected with school related issues and developing friendships. Adolescence brings challenges related to sexuality, growing stigma, growing physical care needs, need for developing self advocacy skills and adulthood, the right to grow up, uncertainty about future, etc.

The four components of family functioning that is a) Family Characteristics and Coping, b) Family Interactions, c) Family Functions, and d) Family life cycle basically interact with each other resulting into a unique family functioning style for each family. This unique family functioning style leads to unique needs for each member of the family having a child with disability. Understanding of all these components and identifying the unique needs is essential before shooting the interventions with the index child and the family. USA by law (P.L. 94- 457) has made it mandatory especially for pre-school programmes to assess the individual needs of each of the family having children with disability below 3 years of age and develop an IFSP (Individualised Family Support Plan).

An Indian tool to assess the individual needs of the family including needs of each of the family members that is parents, siblings and grandparents, NIMH-Family Needs Schedule (NIMH-FAMNS) has been developed (see Chapter-3) and presented in Chapter 8. Also based on NIMH-FAMNS, 'Need based family intervention model' is presented in Chapter 8 of the book.

FAMILY ORIENTED SERVICES

Family in India largely has been and still continues to be the basic unit of social security for any citizen irrespective of disability. Parents and family members fortunately have been naturally involved in the basic care of their mentally retarded children as envisaging or running large residential institutions, they were never economically viable nor did the Indian culture foster the earlier western trend of separating the child from the family. Feeling the need for systematic services beyond 'love and care' Mrs.H.Jai Vakeel mother of a daughter with mental retardation, started a school for Children in Need of Special Care in 1944. The 'family' has been the initiator of the services for the mentally retarded individuals in India, leading presently to about 572 centres of services for mentally handicapped individuals. Unfortunately, the services still continue to be basically child oriented, that is, the emphasis is still largely on child skill training rather than on helping build strengths and facilitating coping of the family members

who are the basic care givers and are a permanent resource for people with the disabilities (Peshawaria, 1988).

India is at present passing through a developmental phase for shaping rehabilitation services for the mentally handicapped. The focus basically is on spread of services and producing trained manpower of different levels of workers, and encouraging involvement of parents of mentally handicapped children in the training and habilitation programmes. Major trends and models of family oriented services presently available in the country for the mentally handicapped individuals and their families are listed (Peshawaria & Menon, 1991).

a) Parent Training Programmes

Emphasis on involving parents has long been emphasized (Prabhu, 1968) and also later by Peshawaria, et al (1989), O'Toole (1989), Hornby and Peshawaria (1991) wherein the researchers discussed about the needs and benefits of involving and working with parents. Few concerted efforts have been made by Parikh & Yadav (1970), Mehta & Ochaney (1984), Date (1986), Kaushik (1988), Mehta et al (1990), Peshawaria (1989), Peshawaria et al (1991) to train parents in the skills to train their children with mental handicap. Peshawaria et al (1991) described the Group Parent Training model, which was used to train parents in specific knowledge and skills. Efficacy of such group parent training programmes were also highlighted. Realising the need and importance of involving and training parents, National Institute for the Mentally Handicapped (NIMH) at Secunderabad started Group Parent Training Programmes on regular basis i.e. on quarterly basis for a group of 30-40 parents from the year 1988 which are still continued. Every year 10 to 12 such group parent training programmes are conducted on workshop lines at NIMH. Both parents, mother and father are encouraged to attend the programme. Such programmes provide a forum for parents for mutual support of parents and exchange of ideas. Through these programmes parents do come to realise their strengths in managing their mentally handicapped child which earlier they thought could only be handled by professionals. Care is taken not to conduct programmes in a way that parents feel de-skilled, instead efforts are made to help parents to

realise their potential which could be used for the benefit of their mentally handicapped child and themselves. Such parent training programmes have become very popular. Apart from conducting Group Parent Training Programmes on regular basis at NIMH, the staff of NIMH also conduct nearly 10-12 such group parent training programmes every year across in the country on the request of non-governmental organisations.

b) Parent Movement

The last decade has seen an upsearch of parents coming together and forming support groups in order to initiate, promote or support rehabilitation services for the mentally retarded individuals and their families. Such parent movement which is now catching up helps immensely in providing direction to the service provision, and in bringing about transparency of the available services to the mentally handicapped individuals and their families. Various reasons have brought parents together which include non-existence of required services such as training facilities for their mentally retarded individuals, not satisfied with the quality of services available, nature and type of services do not match with the needs of their children and families, trying to find solutions to one of the major concerns "What after parents are no more there" and meeting their own emotional needs and exchange of awareness and informations. Some well meaning parents who are altruistic in nature, are financially more comfortable following retirement from jobs, have time to spare or want to use their time meaningfully or parents who have been motivated through contact with devoted professionals are the ones who are seen to be the forerunners of such parent movement in the country.

Presently 43 registered parent organisations are working for the welfare of the mentally handicapped individuals in the country. The first one was formed in Ahmedabad in the state of Gujarat in the year 1968. Presently 15 out of 32 states & UTs in India have such registered Parent Organisations. Till 1980 there were only 2 registered parent organisations in the country. Presently 13 parent organisations are existing in Andhra Pradesh itself followed by 6 in the state of Maharastra and so on (Peshawaria et al 1994). November, 1994 witnessed another milestone in the history of parent

movement in India through the initiation of National Parent Body with an adhoc working committee soon to be formalised and named as "National Federation of Parents Associations" established with the technical support by National Institute for the Mentally Handicapped, Secunderabad. Parent Organisations are actively involved in a number of activities such as establishing and running various services for the mentally handicapped persons and their families, supporting professionals in various capacities, establishing links with the community, acting as advocates and participating in policy making both at national and international levels. Keeping the present enthusiasm amongst the parents and their growing awareness of the situation as also of their rights, gaurdians of service provision for the mentally handicapped individuals and their families need to be prepared to take on them greater challenges than ever before. Sincere and concerted efforts will have to be made in developing constructive and meaningful parent professional partnerships.

c) Sibling Groups

Efforts though scattered and scanty are being made to promote the involvement of siblings of children with mental handicap. However, this has not been a major focus and has not yet become an integral part of the regular service provision. Sibling groups are being organised in which siblings are involved in conducting various leisure activities during holiday times for their brothers and sisters with mental handicap. They are also being encouraged to participate in the training and habilitation programmes and awareness building programmes. Sibling involvement is considered to help siblings become aware of the various needs and strengths of their brothers and sisters with mental handicap and promote healthy integration and interaction fostering normalisation for the mentally handicapped individuals apart from meeting their own personal needs of adaptation.

d) Family Cottages

NIMH started Family Cottage Services on the campus basically to cater to the needs of outstation families for whom appropriate services may not be available in their setting. Facilities are provided wherein parents and other family members including siblings and grandparents along with their

mentally retarded child are admitted temporarily into the cottage for 1-3 weeks depending upon their needs. The focus is both to promote the child's training and also on meeting the individual needs of parents and other family members to promote healthy family functioning. Such kind of brief residential programmes for the parents/families are being provided at Vellore (Date, 1986) and Bangalore (Girimaji, 1993).

e) Other Service Models

Different other models of working with parents are of evidence in India. **Home based programmes** where itinerant workers make periodical home visits to guide the parents are not very popular in Indian setting, basically because it is an expensive model in terms of professional time and money. Models which can handle groups of parents or groups of children with mental handicap are more feasible in the Indian context, though knowing well that such group models cannot totally replace working on a one to one basis. **Centre based individual model** which is becoming one of the popular model is generally used in Child Guidance Clinics and institutions providing individual based interventions carried out by a multi-disciplinary team of experts. In this model, as is available at NIMH, Secunderabad a management programme is designed by various professionals for the parents as per the needs of the child in order for them to carryout the programme at home. Each family alongwith their child with mental retardation have the opportunity to work out their individual concerns on a one to one basis. **Centre based group activities:** This model was adopted at NIMH precisely to reach out to large numbers of children with mental handicap due to paucity of devices in the twin cities of Hyderabad and Secunderabad. The focus is more on the child's learning. Parents are encouraged to attend group activities along with their child and serve as mediators in training their children.

RESEARCH WITH FAMILIES

Research in understanding of families and working with the families in the true sense is still eluding Indian scene. For long, emphasis was on studying the epidemological aspects. Parents of mentally retarded individuals rather than the whole family including siblings and grandparents

have been the main target for study by a few researchers. Major focus has been studying the attitudes of parents towards the mentally retarded child (Rastogi, 1981; Bhatti et al, 1985; Channabasavanna et al, 1985; Devi, 1976; Hariassara, 1981; Srivastava, 1978; Mazumdar & Prabhu, 1972; Chaturvedi, S.K., & Malhotra, S., 1983; Chaturvedi, S.K., & Malhotra, S.,1984). Prabhu (1970) studied the needs of parents in terms of reasons for institutional placement. Impact on the parents was studied by Seshadri et al, (1983), Sequiera et al, (1990), Sethi & Sitholey, (1986), Tangri & Verma, (1992), Wig et al, (1985). A study investigating social emotional support for parents was presented by Moudgil et al (1985); Treatment seeking behaviour of parents (Chaturvedi and Malhotra 1982); Consumer demand of services by parents (Peshawaria and Venkatesan); and Parent needs was presented from a conceptual framework (Peshawaria and Menon 1991). Studies related to Parent involvement and Parent training are mentioned earlier in the text under the subtitle of Parent Training. On reviewing the available Indian literature there is paucity of information on scientific understanding of 'Indian families having mentally retarded individuals' which should necessarily include mother, father, brothers, sisters and grandparents.

Systematic work with Indian families also have yet to be initiated in the country. By systematic work is meant that each "Family" having a child with mental retardation which seeks out for services, their needs are assessed, based on identifying individual needs of different members of the family. Family Intervention Programme Plan is developed, implemented and evaluated. It is precisely to encourage and initiate such systematic services in the country and promote scientific research in the area of understanding and working with Indian families having mentally retarded individuals that information in following chapters is shared.

REFERENCES

Bhatti, R.S., Channabasavanna, S.M. & Prabhu, L.R. (1985). **A tool to study the attitudes of parents towards the management of mentally retarded children.** Child Psychiatry Quarterly, 18, 35-43

Berger, M. & Foster, M. (1986). **Applications of family therapy theory to research and interventions with families with mentally retarded children**, in Families of Handicapped Persons: Research, Programs and Policy Issues, (eds.J.J.Gallagher and P.M.Vietze) Paul H.Brookes, Baltimore, pp.251-60.

Bron Fenbrenner, U. (1977). **Towards an experimental ecology of human development.** American Psychologist, 32(7), 513-31.

Bronfenbrenner, U. (1979). **The ecology of human development.** Cambridge, MA: Harvard University Press.

Bubolz, M.M., & Whiren, A.P. (1984). **The family of the handicapped: An ecological model for policy and practice.** Family Relations, 33,5-12.

Channabasavanna, S.M., Bhatti, R.S., & Prabhu, L.R. (1985). **A study of attitudes of parents towards the management of mentally retarded children.** Child Psychiatry Quarterly, 18, 44-47.

Chaturvedi, S.K., & Malhotra, S. (1982). **Treatment seeking behaviour of parents of mentally retarded children.** Indian Journal of Clinical Psychology. 9: 211-216.

Chaturvedi, S.K., & Malhotra, S. (1983). **Parentaal attitudes towards mental retardation.** Child Psychiatry Quarterly, 16(3), 135-142.

Chaturvedi, S.K., & Malhotra, S. (1984). **A follow-up study of mental retardation focusing on parental attitudes.** Indian Journal of Psychiatry, 26(4), 370-376.

Chilman, C.S., Nunnally, E.W. & Cox, F.M. (eds) (1988). **Chronic Illness and Disability.** Sage, Newbury Park, CA.

Date, S. (1986). **Parent training for the care of the mentally retarded.** Community Mental Health News, 7: 3-4.

Devi, A.V.S., (1976). **Short communication on parental attitudes towards retarded children.** Child Psychiatry Quarterly, 9(2), 10-12.

Girimaji, R.S.C.(1993). **Family intervention in Mental retardation - An overview.** NIMHANS Journal, 11(1), January 1993, 21-26.

Hariasara, M. (1981). **A developmentally handicapped child in the family: Parent perception, attitudes and their participation in the programme.** Mental Health Review 1(2), 55-60.

Hornby, G & Peshawaria, R (1991). **Teaching counselling skills for working with parents of mentally handicapped children in a developing country.** International Journal of Special Education, 6,(2) pp.231-36.

Kaushik S.S. (1988). **Parents as teachers, A study in behaviour modifications of mentally subnormals.** New Delhi: Northern Book Centre.

Mazumdar, B.N. & Prabhu, G.G. (1972). **Mental retardation: Parent's perception of the problem.** Child Psychiatry. Q.5:13-18.

Mehta, M., & Ochaney, M. (1984). **Training mental retardates, involving mothers in operant conditioning programme.** Indian Journal of Clinical Psychology, 11(12), 45-49.

Mink, I.T. & Nihira, K. (1987). **Direction of effects: Family life styles and behaviour of TMR children.** American Journal of Mental Deficiency. 92(1), 57-64.

Mitchell, D. (1983). **Guidance needs and counselling of parents of mentally retarded persons.** In N.N.Singh & K.M.Wilton (Eds.), Mental retardation: Research and services in New Zealand, Christchurch, New Zealand: Whitoculls.

Moudgil, A.C., Kumar, H & Sharma, S. (1985). **Buffering effect of social-emotional support on the parents of mentally retarded children.** Indian Journal of Clinical Psychology, II: pp.63-70.

Olson, D.H., McCubbin, H.I., Barnes, H., Larsen, A., Muxen, M., & Wilson, M. (1984). **One thousand families: A national survey.** Beverly Hills, CA: Sage.

O'Toole, B. (1989). **The relevance of parental involvement programmes in developing countries.** Child: Care, Health and Development, 15, pp. 329-342.

Peshawaria, R. (1988). **Guidance and counselling for parents of mentally handicapped persons.** Update in Mental Retardation, Material for Second Refresher Course, NIMH, May, 16 to June 3, 1988.

Peshawaria-Menon, R. (1989). **Parent involvement in the training and management of their mentally handicapped persons**. Journal of Personality & Clinical Studies, 5,2,pp.217-221.

Peshawaria, R., Venkatesan, S. & Menon, D.K. (1988). **Consumer demand of services by parents of mentally handicapped individuals**. Indian Journal of Disability and Rehabilitation, July-December, pp.43-57.

Peshawaria, R., Menon, D.K. (1991). **Needs of the families of mentally handicapped children.** Indian Journal of Disability and Rehabilitation.

Peshawaria, R., Reddi, V.S., Subba Rao, T.A. & Persha, A.J. (1991). **Group parent training programmes at NIMH: An overview.** J. Journal of Personality and Clinical Studied 7: 169-174.

Peshawaria, R., Menon, D.K., & Reddy, S.H.K. (1994). **Directory of Parent Associations for the Welfare of the Mentally Retarded Persons in India**. National Institute for the Mentally Handicapped, Secunderabad-500 009. India.

Peshawaria, R. & Menon, D.K. (1991). **"Theory and practice - Working with the families of children with mental handicap in India: various models.** Counselling Psychology Quarterly, Vol.4, NO.4. pp.345-350.

Prabhu, G.G., (1968). **The participation of the parents in the services for the retarded.** Indian Journal of Mental Retardation, Vol.1. No.1, pp. 4-11.

Prabhu, G.G.(1970). **A study of parents needs for institutional facilities for the retarded**. Indian Journal of Mental Retardation, 3:21-24.

Rastogi, C.K. (1981). **Attitudes of parents towards their mentally retarded children.** Indian Journal of Psychiatry, 23: 206-209.

Seshadri,M., Verma, V.K., Verma, S.K., & Pershad. D.(1983). **Impact of a mentally handicapped child on the family.** Indian Journal of Mental Retardation, 473-478.

Sequiera, E.M., Rao, P.M., Subbukrishna, D.K. & Prabhu, G.G. (1990). **Perceived burden and coping styles of mothers of mentally handicapped**. NIMHANS Journal, 8(1), 63-67.

Sethi, B.B. & Sitholey, P. (1986). **A study of time utilisation, perception of burden and help expectations of mothers of urban mentally retarded children**. Indian Journal of Social Psychiatry, 2(1&2), 25-44.

Srivastava, R.K, (1978). **Attitudes of mothers of mentally retarded children towards certain aspects of child rearing patterns.** Indian Journal of Mental Retardation, 11(2), 64-74.

Tangri, P. & Verma, P. (1992). **A study of social burden felt by mothers of handicapped children.** Journal of Personality and Clinical Studies, 8(1&2), 117-120.

Turnbull, A.P., & Turnbull, H.R. (1986). **Families, professionals, and exceptionality**, Columbus, OH:Merrill.

Turnbull, A.P., Summers, J.A. & Brotherson, M.J. (1984) **Working with families with disabled members**. University of Kansas Press, Kansas.

Von Bertalanffy, L. (1968). **General systems theory**. New York: George Braziller.

Wig, N.N., Mehta, M. & Sahasi, G. (1985). **A study of time utilisation and perceived burded of mentally handicapped child in joint and nuclear families.** Indian Journal of Social Psychiatry, 1, 251-261.

Parents may find comfort, I say, in learning that their children are not useless, but that their lives, limited as they are, are of great potential value to human race. We learn as much from illness as from health, from handicaps from advantage - and indeed perhaps more.

Pearl S.Buck

CHAPTER 2

Parents : Impact

INTRODUCTION

Parenting a child with mental retardation is not an easy job (Peshawaria, 1992). Parents having a child with mental retardation experience a variety of stressors and stress reactions related to the child's disability (Orr et al., 1993). Parents are known to get impacted in many ways because of having a child with mental retardation. These include, parents feeling sad, depressed at various stages of child's life and experiencing other emotional reactions. Their social life may get affected with recreational and leisure activities getting reduced. Interpersonal relationships with the family members, friends and others also get affected. Marital harmony gets disturbed owing to various child related reasons such as meeting extra-child care responsibilities and burden, affecting sexual relationships between parents due to less privacy, more fatigue and fear of producing another child with disability. Financial burdens may mount. Parents' own physical and mental health is reported to be at a greater risk. However, the quality and quantity of the impact experienced may be quite individualized for each of the parents depending upon the nature of support available to them such as emotional, physical or financial support. Other factors such as coping skills of parents themselves, child characteristics such as age, level of mental retardation, presence and absence of associated conditions etc. may also contribute

immensely how far parents are able to face the challenge of having a child with mental retardation.

Although the passage of time will mitigate the effects of some stressors on parents and make their responses to stressful situations more routine, it is also possible that with the changing nature of the child and increased expectations associated with growing older, the magnitude of stress that parents experience may increase (Orr et al., 1993).

CONCEPTUAL FRAMEWORK

The impact of a disabled child on the parents has been well documented. Emotional reactions are the most commonly cited impact due to the presence of a child with mental retardation in the family (Olshansky, 1962; Kaslow & Cooper, 1978; Evans, 1979; Cunningham, 1979; Beckman-Bell, 1981; Blacher, 1984; Wickler 1986; Bristol, 1987). Although, there will be always individual differences in the reactions of each of the parents, usually they are known to pass through a sequence of stages of reactions like shock, denial, grief, anger etc. after knowing the diagnosis of disability in their child.

The impact of children with disabilities on parents and other family members has long been of interest to professionals. Consequently understanding of relationships within the family has grown considerably over time. Currently families are viewed as interactive, interdependent systems with individual members reciprocally affecting each other, such that anything which affects one member of the family will have some impact on all other members and therefore on the family as a whole (Marshak & Seligman, 1993). Research has documented that the child with mental retardation may also influence functions related to meeting basic family needs, economic needs, daily care needs, recreation needs, socialization needs, self identity needs etc. The presence of the child with mental retardation can cause financial hardships for families by increasing the family's consumptive demands and decreasing its productive capacity (McAndrew, 1976; Kaslow & Cooper, 1978; Londsdale, 1978; Turnbull et al., 1984). The responsibilities associated with the care of children with mental

retardation may impact the parents' psychological, physical and financial well being over time (Seligman & Meyerson, 1982; Ventura & Boxx, 1983; Gallagher et al., 1983; Quine & Paul, 1985). The presence of a child with mental retardation may also curtail the recreation needs of the family (Dunlap & Hollingsworth, 1977; Londsale, 1978). The child with mental retardation often imposes social restrictions on the family (McAndrew, 1976; Roos, 1977; Wickler, 1981, Strain, 1982; Skrtic et al., 1984, Vadasy et al., 1984; Brotherson, 1985; Goldfarb et al., 1986). Parents may also develop low self esteem as a result of having a child with mental retardation (Cummings, Bayley, & Rie, 1966; Rousso, 1984; Turnbull & Turnbull, 1990).

The child with mental retardation may also influence the interactions and relationships between the parents. Studies have indicated that having a child with mental retardation can have negative impact on the parent's marriage (Reed & Reed, 1965; Gath, 1977; Featherstone, 1980; Murphy, 1982). In addition, research with mothers and fathers suggests that the presence of a child with mental retardation can alter traditional expressive or instrumental roles parents are accustomed to (Gumz & Gubrium, 1972; Gallagher et al., 1981). Although most of the studies have indicated negative effects in the family because of having a child with mental retardation, few studies have also indicated the positive effect. Positive effects reported include stronger marriage (Summers, 1987), more tolerance and patience.

Although 3 % of the general population of 900 million have mental retardation in India, there is a paucity of systematic research related to understanding the impact of the child with mental retardation on the family. Research in India on the families having a child with mental retardation has focussed mainly on the various socio-psychological variables which are contributory to mental retardation (Ishtiaq, 1977). However, there are a few studies in India that have demonstrated that the presence of a child with mental retardation can cause emotional reactions like shock, guilt etc. (Seshadri, et.al., 1983; Narayan, 1979), increase in interpersonal conflicts among family members (Jain & Sathyavathi, 1969), social isolation (Narayan, 1979) and added responsibilities (Jain & Sathyavathi, 1969). So

far there has been no such study in India that has analysed the impact of a child with mental retardation on his/her family using a life cycle approach. The present study presents results of the study undertaken to analyze the impact of a child with mental retardation on his or her parents

METHODOLOGY

Sample

The sample included families of 120 children with mental retardation. The sample consisted of 103 fathers and 115 mothers. The mean age of the sample was 41.5 years (SD = 8.91). 49.1% of the sample had completed education upto degree and above, 50.9 % of the sample had education below degree. The mean family income of the sample per month was Rs 3242.70 (SD = 2591.5). Status of 98 families was nuclear and for 22 families non-nuclear. While 79 families were living in urban areas, 41 families were living in rural and slum areas.

The mean chronological age of individuals with mental retardation was 13.10 years (SD = 7.51). Of the 120 individuals, 84 (70%) were male and 36 (30%) were female. 27.3 % had mild mental retardation (I.Q = 50-69), 48.3% of index individuals had moderate mental retardation (I.Q = 35-49), and 24.2% had severe mental retardation (I.Q < 35).

All families were identified by the collaborating centres; namely Balavikas, Trivandrum; Navjyothi Centre, Delhi; and Digdarshika, Bhopal. Forty families were drawn from each of these three centres in the following ways:

- Letters describing the study and requesting parental participation were provided by the research staff of the collaborating centers to the child guidance clinics/special schools/vocational centers in their respective cities. Altogether, 15 special schools, 10 child guidance clinics and 8 vocational training centers providing services to individuals with mental retardation were contacted.

- Of all the centers contacted, 10 special schools, 5 child guidance clinics and 5 vocational centers showed interest to participate in the study. Each of the centers submitted to the research staff a list of 20 potential participants for the project.

- Letters describing the purpose of the study, method of collecting information, protection of confidentiality and total time required to collect information was sent to all the 400 participants.

- Responses were received from 185 families. Purposive sampling was done in the selection of 120 families based on the mutually defined inclusion criteria and also to have adequate representation in subgroups of variables of age, sex, severity, etc., as illustrated below:

i. **The child with mental retardation was living with his/her biological parents at home.**

ii. **Age of the individual with mental retardation.**
It was agreed that 25 % of the sample i.e., 30 families should include families having children with mental retardation belonging to each of the various age groups i.e., birth-6 years, 7-12 years, 13-18 years and 19 years and above.

iii. **Dropouts or not receiving any services.**
It was agreed that a minimum of 25 % of the sample should include families of children with mental retardation who were dropouts or not receiving any services.

iv. **Geographic location**
It was agreed that a minimum of 25 % of the sample should include families of children with mental retardation living in the non-urban area (rural and slums).

Table 2.1, Table 2.2 and Table 2.3 present the detailed demographic information of the sample according to handicapped child, parent and family characteristics.

TABLE 2.1
CHARACTERISTICS OF MENTALLY RETARDED INDIVIDUALS

Sl. No.	Variable	Child Characteristics				Total (%)	Mean (S.D)
1.	Age(Yrs)	0-6	7-12	13-18	19+		
	n	30	30	30	30	120	13.10
	(%)	(25)	(25)	(25)	(25)	(100)	(7.51)
2.	Sex	Male		Female			
	n	84		36		120	
	(%)	(70)		(30)		(100)	
3.	Severity	Mild	Moderate	Severe			
	n	33	58	29		120	
	(%)	(27.5)	(48.3)	(24.2)		(100)	
4.	Behaviour Problems	Present		Absent			
	n	53		67		120	
	(%)	(44.2)		(55.8)		(100)	
5.	Services	Attending		Not Attending			
	n	83		37		120	
	(%)	(69.2)		(30.8)		(100)	

TABLE 2.2
PARENT CHARACTERISTICS HAVING MENTALLY RETARDED INDIVIDUALS

Sl. No.	Variable	Parent Characteristics			Total (%)	Mean (S.D)
1.	Age(Yrs)	< =35	36-50	>50		
	n	63	122	33	218	41.5
	(%)	(28.9)	(55.9)	(15.2)	(100)	(8.91)
2.	Sex	Mother		Father		
	n	115		103	218	
	(%)	(52.7)		(47.3)	(100)	
3.	Education	Primary	Sec-Inter	Degree		
	n	36	75	107	218	
	(%)	(16.5)	(34.4)	(49.1)	(100)	

TABLE 2.3
FAMILY CHARACTERISTICS OF MENTALLY RETARDED INDIVIDUALS

Sl. No.	Variable	Family Characteristics		Total (%)	Mean (S.D)
1.	Nature of Family	Nuclear	Non Nuclear		
	n	98	22	120	
	(%)	(81.7)	(18.3)	(100)	
2.	Income per month	< = Rs.1000	>Rs.1000		
	(in Rs.) n	55	65	120	3242.7
	(%)	(45.9)	(54.1)	(100)	(2591.5)
3.	Area of Residence	Urban	Non-Urban		
	n	79	41	120	
	(%)	(65.8)	(34.2)	(100)	
4.	Outside help for Household work	Available	Not-available		
	n	49	71	120	
	(%)	(40.8)	(59.1)	(100)	

Procedure

All the interviews were conducted by the research staff in the homes of the participants included in the study. All the 103 fathers and 115 mothers were interviewed individually at their residence. The research staff involved in conducting the interviews included the third author of this book and two M.Phil level psychologists. All of them had received training on interview techniques.

The methodology used in the present study was essentially field survey to identify the impact on the parents i.e. mothers and fathers because of having a child with mental retardation relevant to Indian setting. The interview was conducted focussing on the impact on the parents because of having a child with mental retardation. Parents were asked individually open ended question to elicit information on the impact of having a child with mental retardation:

> *"How do you think having a son/daughter with mental retardation has affected you?"*

The question related to the impact was followed by probes related to identifying parental needs. Each interview with the mother or father lasted about 15-30 minutes depending upon how elaborate the respondent was. All the interviews were tape recorded with prior permission.

Measurement

All the responses to the open ended question related to impact were coded and jointly placed in categories for 118 parents by the first, third and fourth authors of this book. The categories were defined in a way that would facilitate intervention. For the remaining 100 parents, the first, third and fourth authors independently classified the responses into categories and inter-rater reliability established. Inter-rater reliability of 96.8 %, was obtained. It may be noted that when a single parent reported number of responses which belonged to a single category, it was scored only once in the given category. For example, in the category of, "Emotional Reactions", one

parent may have reported that she felt demoralised, sad and angry because of having a child with mental retardation. All these responses were rated under "Emotional Reactions" and given a score of 1. Descriptive statistics (percentages) and chi-square tests were used to analyze and compare the results.

FINDINGS AND OBSERVATIONS

Table: 2.4 provides definitions of categories related to the impact felt by the parents of children with mental retardation.

TABLE 2.4
DESCRIPTION OF IMPACT CATEGORIES

1. **Problem:Professionals (callous/negative)**
   1. Doctor
   2. Vocational Trainers
2. **Unhappy/desperation due to no information provided about child's condition**
   1. During the initial stages
   2. Vocational Training
   3. Marriage
3. **Emotional Reactions**
   1. Shock
   2. Anger
   3. Denial
   4. Sadness/Depression
   5. Guilt
   6. Tension
   7. Demoralized
   8. Indifferent
4. **Extra Demands**
   1. Care Physical
   2. Financial/debts
   3. Overworked
   4. Consultations
5. **Indecisiveness (what to do? what not to do?)**
6. **Career Adjustments (mother/father)**
   1. Sought transfer
   2. Less paid job
   3. Can't take up job
   4. Left Govt. job
   5. Readjustment timings of job
7. **Mental Worries due to**
   1. Marriage of the child
   2. Future
   3. Having such a child in the family
   4. Poor academic achievement
   5. Girl child

8. **Change of Residence**

9. **Loss of Support from**
   1. Spouse
   2. In-laws
   3. Relatives
   4. Neighbours
   5. Community
   6. Peers
   7. Colleagues

10. **Social Restrictions**
    1. Inability to attend social functions

11. **Strained Relationship**
    1. Friends
    2. Relatives
    3. Neighbours
    4. In-laws
    5. Family
    6. Spouse

12. **Effect on siblings**
    1. Less time for siblings
    2. Studies get affected

13. **Thoughts of killing the child**

14. **Face Ridicule**
    1. Within the family
    2. Community

15. **Embarrassment due to child's behaviour**

16. **Over-indulgence**

17. **Forced separation of the MR child from family**

18. **Psychosomatic problems**
    1. High BP
    2. Sleeplessness
    3. Headache

19. **Attempted suicide**

20. **Restriction in family size**
    1. Fear of giving birth to another MR child

21.. **Positive effects**
    1. More patience
    2. Tolerance

The frequency distribution in percentages of the various types of impact (in descending order) reported by parents in a family having a child with mental retardation are presented in Fig. 2.1

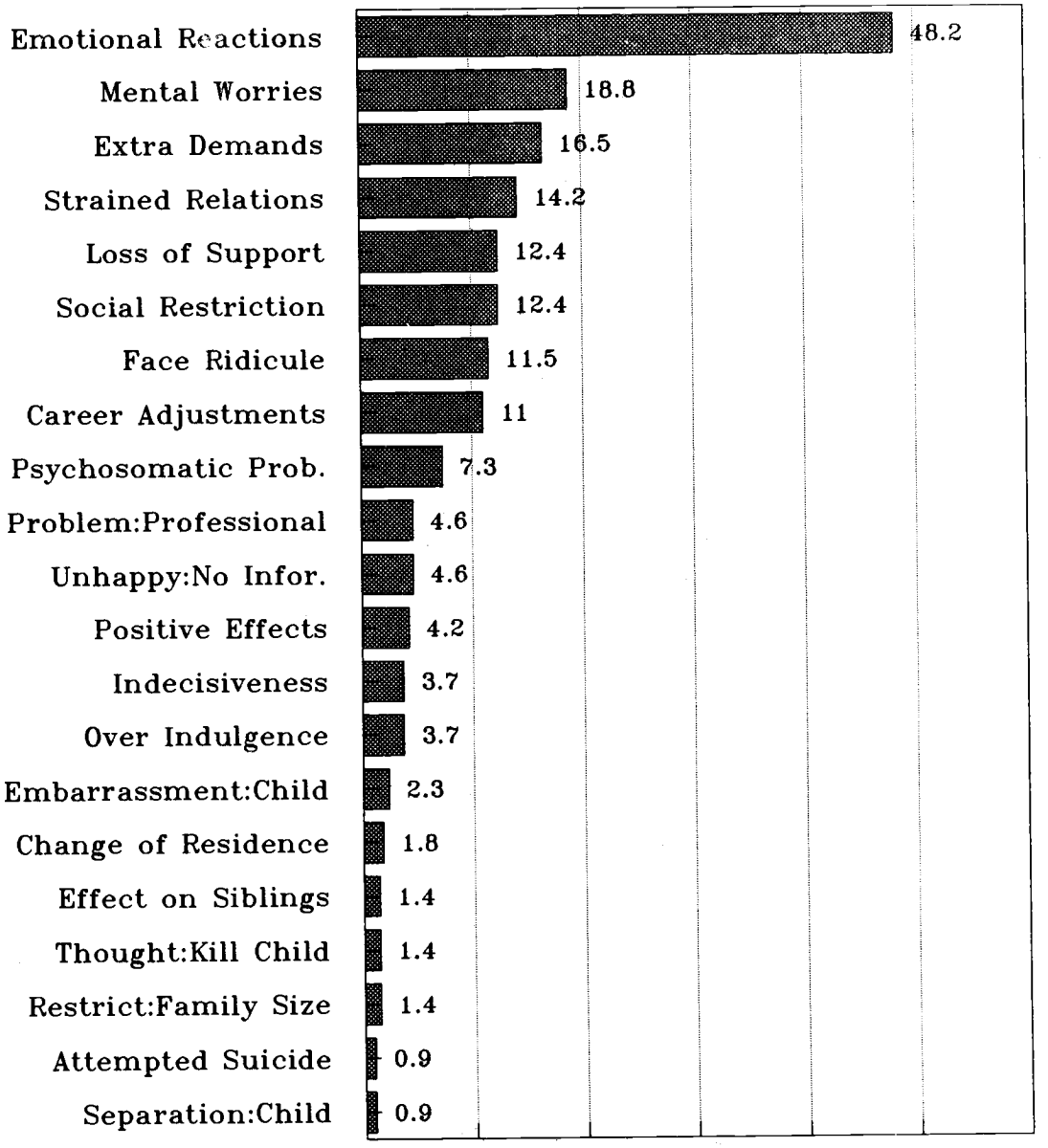


Fig. 2.1
PERCENTAGE ENDORSEMENT OF
IMPACT REPORTED BY PARENTS

Data indicate that parents reported wide ranging experiences because of having a child with mental retardation. Emotional reactions like sadness, depression, denial, anger etc. were reported by maximum number of parents because of having a child with mental retardation. Results indicated that parents felt worried, had to cater to extra demands, had psychosomatic problems, felt burdened with extra-child care demands. Parents also reported experiencing strained relationships from extended family members and loss of support from family members. Some parents reported being ridiculed within the family and in the community and also had to plan career adjustments.

The types of impact felt by parents were analyzed on three variables related to parents namely age, sex and education level; four variables related to child's age, sex, severity of mental retardation and presence of behaviour problems; and three variables related to family i.e., family income, nature of family: nuclear/non-nuclear and area of residence:urban/non-urban.

Parent Variables

The pattern in the type of impact, related to **parent variables**, felt by parents due to the presence of a child with mental retardation in the family is presented in Table 2.5.

Results indicate and confirm that having a child with mental retardation does have a tremendous effect on both the parents. Both, mothers and fathers seem to undergo immense emotional turmoil. Mothers, however, experienced significantly greater loss of support, than the fathers. Fathers perceived significantly greater impact in terms of "change of residence", and "thoughts:kill the child". Observations on comparing the percentages does indicate that mothers get affected more in terms of making compromise such as "career adjustment" or "losing out on recreation" i.e., "social restriction". Fathers feel more burdened with "extra demands" due to greater financial problems and extra care responsibilities.

TABLE 2.5
PERCENTAGE ENDORSEMENT OF IMPACT ON PARENTS : PARENT VARIABLES

Sl. No.	Impact : Parents	Parent Variables (N=218)							
		Age (In Years)			Sex		Education		
		< =35 (n=63)	36-50 (n=122)	>50 (n=33)	Mother (n=115)	Father (n=103)	< = Primary (n=36)	Secon-Inter (n=75)	Degree + (n=107)
1.	Problem:Professional	3.2	4.9	6.1	4.3	4.9	5.6	4.0	4.7
2.	Face Ridicule	6.3	12.3	18.2	12.2	10.7	5.6	12.0	13.1
3.	Emotional Reactions	41.3	53.3	42.4	48.7	47.6	30.6	38.7	60.7***
4.	Extra Demands	12.7	18.0	18.2	14.8	18.4	19.4	16.0	15.9
5.	Indecisiveness	3.2	4.1	3.0	3.5	3.9	0.0	5.3	3.7
6.	Career Adjustments	17.5	7.4	12.1	13.0	8.7	8.3	13.3	10.3
7.	Mental Worries	23.8	14.8	24.2	18.3	19.4	30.6	17.3	15.9
8.	Change:Residence	0.0	1.6	6.1	0.0	3.9**	0.0	2.7	1.9
9.	Loss of Support	17.5	9.8	12.1	17.4	6.8*	13.9	17.3	8.4
10.	Social Restrictions	11.1	13.9	9.1	13.0	11.7	5.6	13.3	14.0
11.	Strained Relationship	19.0	10.7	18.2	13.0	15.5	11.1	14.7	15.0
12.	Effect:Siblings	3.2	0.8	3.0	0.9	1.9	2.8	0.0	1.9
13.	Thought : Kill Child	0.0	2.5	0.0	0.0	2.9*	2.8	0.0	1.9
14.	Unhappy : No Information	3.2	4.9	6.1	4.3	4.9	5.6	5.3	3.7
15.	Embarrass:Child	3.2	2.5	0.0	1.7	2.9	0.0	1.3	3.7
16.	Over Indulgence	3.2	3.3	3.0	2.6	3.9	0.0	5.3	2.8
17.	Separation : Child	0.0	0.8	3.0	0.9	1.0	0.0	1.3	0.9
18.	Psychosomatic Problems	1.6	6.6	21.2*	7.8	6.8	8.3	5.3	4.7
19.	Attempted Suicide	0.0	1.6	0.0	0.9	1.0	0.0	1.3	0.9
20.	Restrict:Family size	1.6	1.6	0.0	1.7	1.0	0.0	0.0	2.8
21.	Positive Effects	1.6	3.3	9.1	3.5	3.9	2.8	1.3	5.6

* p < 0.05, ** p < 0.01, *** p < 0.001

One of the significant findings related to the age of parents indicate that "psychosomatic problems" show a significant increase as the age of the parent advances as also when the age of the child with mental retardation increases. The unresolved emotional reactions coupled with the mental worries related to their child's future concern could be the contributing factors putting parents' physical and mental health at a greater risk. Other reactions of parents such as "problems:professional", "facing ridicule", "extra demands", as also "positive effects" seem to increase with age. Mental worries seem to be more experienced during early years of life (upto 35 years) or later years of life (above 50 years). "Loss of support" from spouse, relatives, friends, in-laws and neighbours as also "strained relationship" is experienced by more younger parents (upto 35 years).

"Emotional reactions" such as sadness, anger, depression and tension show significant relationship with the education level of the parents. Emotional reactions were experienced more by higher educated parents (graduates and above). Parents generally desire and feel satisfied and happy when their children achieve higher than they themselves could in their lives. Probably, higher educated parents feel greater emotional blocks in accepting their children with mental retardation as they don't achieve as per their expectations. Also, attitudes and expectations from others in the community towards them could contribute to their emotional turmoil as results do indicate that higher educated parents face greater "social restriction", "strained relationships" and "face ridicule" from others. Less educated parents on the other hand seem to be burdened more with "extra demands" and "mental worries" because of having a girl child, worries related to child's marriage and future or extra demands such as financial debts and overwork.

Handicapped Child Variables

The data on the type of impact, related to **child variables**, reported by parents due to the presence of a child with mental retardation are presented in Table 2.6.

Results indicated significantly greater impact on the parents because of having a female child than a male child with mental retardation. "Social restrictions" which include non-participation in most social activities were significantly more in parents having a female child with mental retardation. It has been observed in Indian settings that certain issues related to girl child are generally kept as a great secret within the family since parents feel it could affect the future prospects of their child's marriage. Hence, parents prefer to stay away from interacting with others to avoid disclosure of their child's disability. Intense reactions such as "thought:kill child" and "attempted suicide" has been significantly reported more by the parents because of having a daughter with mental retardation as also the "effect on siblings". However, the number of parents reporting these reactions is too small to draw conclusion from it. "Over Indulgence" by the friends, relatives and others is reported significantly higher by the parents having girl child with mental retardation.

TABLE 2.6

PERCENTAGE ENDORSEMENT OF IMPACT ON PARENTS : HANDICAPPED CHILD VARIABLES

Sl. No	Impact : Parents	Handicapped Child Variables (N=218)										
		Age (In Years)				Sex		Severity of MR			Behaviour Problems	
		0-6 (n=54)	7-12 (n=54)	13-18 (n=58)	19+ (n=52)	Male (n=151)	Female (n=67)	Mild (n=60)	Moderate (n=105)	Severe (n=53)	Present (n=93)	Absent (n=125)
1.	Problem:Professional	5.6	3.7	5.2	3.8	4.6	4.5	5.0	4.8	3.8	4.3	4.8
2.	Face Ridicule	9.3	3.7	22.4	9.6*	11.9	10.4	6.7	20.0	7.5*	15.1	8.8
3.	Emotional Reactions	48.1	53.7	44.8	46.2	50.3	43.3	61.7	41.9	45.3*	57.0	41.6*
4.	Extra Demands	14.8	7.4	20.7	23.1	17.9	13.4	15.0	20.0	11.3	19.4	14.4
5.	Indecisiveness	0.0	5.6	5.2	3.8	4.6	1.5	3.3	2.9	5.7	4.3	3.2
6.	Career Adjustments	7.4	13.0	6.9	17.3	11.9	9.0	16.7	8.6	9.4	15.1	8.0
7.	Mental Worries	22.2	16.7	19.0	17.3	19.9	16.4	15.0	21.9	17.0	18.3	19.2
8.	Change:Residence	1.9	0.0	3.4	1.9	2.6	0.0	0.0	2.9	1.9	2.2	1.6
9.	Loss of Support	13.0	20.4	5.2	11.5	13.2	10.4	21.7	8.6	9.4*	9.7	14.4
10.	Social Restrictions	7.4	13.0	19.0	9.6	7.3	23.9***	8.3	11.4	18.9	10.8	13.6
11.	Strained Relationship	20.4	11.1	6.9	19.2	16.6	9.0	20.0	8.6	18.9	12.9	15.2
12.	Effect:Siblings	0.0	1.9	3.4	0.0	0.7	3.0*	1.7	1.0	1.9	2.2	0.0
13.	Thought : Kill Child	1.9	0.0	1.7	1.9	0.7	3.0*	3.3	0.0	1.9	1.1	1.6
14.	Unhappy : No Information	3.7	3.7	5.2	5.8	4.6	4.5	3.3	4.8	5.7	3.2	5.6
15.	Embarrass:Child	0.0	9.3	0.0	0.0**	2.6	1.5	8.3	0.0	0.0**	4.3	0.8
16.	Over Indulgence	0.0	9.3	1.7	1.9*	0.7	9.0***	0.0	0.0	13.2***	1.1	4.8
17.	Separation : Child	0.0	0.0	0.0	3.8	1.3	0.0	3.3	0.0	0.0	2.2	0.0
18.	Psychosomatic Problems	0.0	3.7	8.6	17.3**	5.3	11.9	8.3	1.9	17.0**	9.7	5.6
19.	Attempted Suicide	1.9	0.0	1.7	0.0	0.0	3.0**	1.7	0.0	1.9	0.0	1.6
20.	Restrict:Family size	0.0	1.9	3.4	0.0	2.0	0.0	0.0	2.9	0.0	1.1	1.6
21.	Positive Effects	0.0	7.4	1.7	5.8	3.3	4.5	5.0	4.8	0.0	5.4	2.4

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Probably, as it is, worry among parents is observed more when a girl child is born in a family and would be logically greater when having a girl child with mental retardation. To share such concerns of parents, some of the even well meaning friends, relatives do start overindulging and suggesting parents ways of overcoming this difficult situation which many a time hinders than facilitates adaptation of parents. None of the other parental reactions reached statistical level of significance. Trends from the results indicate that parents do try to extend themselves a bit more to meet the needs of their son than their daughter with mental retardation as "extra demands", "career adjustments", "change of residence" , "indecisiveness" are more reported by parents having sons than daughters with mental retardation. "Mental worries" are reported slightly more by parents having sons than daughters with mental retardation. Experience shows that reasons for worrying related to the affected son may be qualitatively different from that of the affected daughter. The issue whether their affected daughter will be able to get married or not can be one of the greatest worries of many parents in India. The daughter according to the Indian culture is generally considered settled in life only if she is married and living with her husband away from her parents. The parents in India are predominantly seen planning and working towards this goal for their daughter right from her birth. On the other hand, the sons are expected to achieve a certain level of independence and status financially and careerwise to become eligible for marriage. Hence, such unresolved expectations from their sons and daughters and seeing no other ways of social security for their affected children can lead parents to worry more, have emotional reactions at times leading to intense destructive thoughts and actions.

Results indicate significantly more "psychosomatic problems" in parents as the age of their child increases . This is also true in relation to parent's age. Unresolved "emotional reactions" and "mental worries" could be significantly contributing towards this. Also, parents have reported significantly greater unhappiness towards the service programs, such as: "Unhappy:no information" especially during the adolescent age of their children. Most of the parents in India reach out for services and help late. It

is also a pointer to the service providers towards the quality and quantity of services matching the needs of the service users. "Overindulgence", "embarrassment:child" and "face ridicule" were reported significantly higher in parents having children with mental retardation between 7-12 years of age probably because behavioural differences between the normal and mentally retarded children become more obvious by this age, making people more inquisitive, critical, concerned or overindulgent.

Parents having children with mental retardation reported significantly greater "loss of support" and "emotional reactions" in comparison to parents having children with moderate to severe and profound mental retardation. Children with mild mental retardation in India generally remain undetected till they reach school going age and find problems in coping up with normal school curriculum. As they generally tend to "look" normal and capable it could be difficult for parents to accept their disability. Hence parents may experience greater emotional reactions. Also emotional reactions as earlier mentioned are significantly higher in parents of children between 7-12 years of age.

Emotional reactions were reported significantly more by parents having children with mental retardation and associated behaviour problems than parents of children with no behaviour problems. It is a well known fact that presence of behaviour problems cause great amount of stress in parents hence higher "emotional reactions".

Family Variables

The patterns in the type of impact, related to **family variables**, felt by parents due to the presence of a child with mental retardation are presented in Table 2.7

Results indicated that joint or extended family can be a boon or a curse for parents having a child with mental retardation. Results showed that either it can drive parents significantly more to attempt suicide or can produce significantly greater "positive effects" in them. However, the number of parents is too small to generalize these observations. None of the

other parental reactions showed statistically significant level of confidence. Trends however indicate that parents living in joint or extended families face greater "extra demands", "career adjustments", "mental worries", "emotional reactions" and "strained relationships". Parents from nuclear families reported "face ridicule", "loss of support" and "social restrictions" . These could be the very reasons for them to live in nuclear family setup.

TABLE 2.7
PERCENTAGE ENDORSEMENT OF IMPACT ON PARENTS : FAMILY VARIABLES

Sl. No.	Reactions : Parents	Parent Variables (N=218)					
		Pattern		Income (In.Rs.)		Area of Residence	
		Nuclear (n-175)	Non-nuclear (n=43)	<=1000/- (n=100)	>1000/- (n=118)	Urban (n=145)	Non-Urban (n=73)
1.	Problem:Professional	4.0	7.0	4.0	5.1	4.8	4.1
2.	Face Ridicule	12.0	9.3	10.0	12.7	12.4	9.6
3.	Emotional Reactions	45.1	60.5	44.0	51.7	61.4	21.9***
4.	Extra Demands	16.0	18.6	13.0	19.5	22.8	4.1***
5.	Indecisiveness	4.0	2.3	4.0	3.4	4.1	2.7
6.	Career Adjustments	9.1	18.6	13.0	9.3	13.1	6.8
7.	Mental Worries	17.7	23.3	22.0	16.1	14.5	27.4*
8.	Change:Residence	1.7	2.3	1.0	2.5	1.4	2.7
9.	Loss of Support	13.1	9.3	20.0	5.9**	11.7	13.7
10.	Social Restrictions	14.3	4.7	10.0	14.4	13.1	11.0
11.	Strained Relationship	12.6	20.9	12.0	16.1	15.2	12.3
12.	Effect:Siblings	1.1	2.3	1.0	1.7	1.4	1.4
13.	Thought : Kill Child	1.1	2.3	0.0	2.5*	1.4	1.4
14.	Unhappy : No Information	5.1	2.3	5.0	4.2	3.4	6.8
15.	Embarrass:Child	2.9	0.0	2.0	2.5	2.8	1.4
16.	Over Indulgence	4.0	0.0	3.0	3.4	0.7	8.2*
17.	Separation : Child	1.1	2.3	0.0	1.7*	1.4	0.0
18.	Psychosomatic Problems	6.3	11.6	10.0	5.1	8.3	5.5
19.	Attempted Suicide	0.0	4.7***	1.0	0.8	1.4	0.0
20.	Restrict:Family size	1.7	0.0	2.0	0.8	2.1	0.0
21.	Positive Effects	2.3	9.3**	2.0	5.1	3.4	4.1

*** p < 0.05, ** p < 0.01, *** p < 0.001**

The area of residence indicated that parents residing in urban cities experienced significantly greater "emotional reactions" and "extra care demands" than parents living in non-urban areas. Possibly, because of the awareness of the condition of mental retardation as also the availability of services for the individuals with mental retardation being higher in urban

areas parents become more aware and hence the greater emotional reactions. Availing services for their children with mental retardation would obviously lead to extra demand on them. The trends show that parents living in urban areas faced greater impact. However, parents residing in non-urban areas significantly reported more "mental worries" related to marriage, future, academic performance of their child and "overindulgence" from others which could be expected probably because of small community living set up.

Income of the family showed that parents from lower income group experienced significantly greater "loss of support" from others due to greater financial demands and problems in coping. Parents of higher income group showed significantly more "thought: kill child" and "separation child". However because of the small number of parents, no definite conclusions can be drawn.

INDICATIONS FOR SERVICE PROVIDERS

- Parents do undergo immense emotional turmoil and suffer from mental worries because of having a child with mental retardation. This prolonged unresolved psychological condition makes them more susceptible to psychosomatic problems. Hence there is a need to make available the necessary counselling services "early"; as soon as the child is identified having mental retardation. The services should be provided on individual basis or through group counselling depending upon individual needs of parents.

- Training of all the service providers in basic counselling and interpersonal skills is absolutely necessary to have better rapport and parent-professional relationship.

- Parent support groups wherein participation of both mothers and fathers need to be encouraged so that parents can share common concerns, learn from each other's experiences and support each other in time of need.

- Service providers should ensure that they are true and honest to the parents while giving information and answering to queries of parents. Wherever needed, professionals should not hesitate in using referral service and follow interdisciplinary approach to meet the diverse needs of parents.

- Intervention programmes need to be focussed on early building and strengthening the natural support systems for the parents. Based on the individual needs of parents and families, counselling must be provided to various members of the family, neighbours, friends and close relatives to gain their continued and long-term support for the family.

- Conduct of community awareness programmes and involving community into the rehabilitation programmes targeting children, adults and aged population would help immensely in shaping and correcting attitudes of the community towards individuals with mental handicap.

- Indigenous support service models acceptable to Indian parents need to be evolved to meet the impact of extra care needs, extra financial needs, career adjustments and future security needs of the children with mental retardation.

- Intervention programmes should aim at empowering parents i.e both mothers and fathers with problem solving skills to enable them to cope effectively to the various challenges faced by them because of having a child with mental retardation. These challenges could be related to their child's training, habilitation or behaviour problem management, handling perceptions and attitudes of people in the family and community or even related to their own emotional reactions, perceptions, expectations or attitudes.

- Efforts need to be made to develop strategies and make available model of services which could facilitate identification of "children at risk" or "children with mental retardation" early to provide need based service to both the child and the family. This will help the professionals to start early and earnestly in shaping the child's learning as also the family's adaptation

process to the situation of having a child with mental retardation. Family focussed early intervention programmes can prevent immense wastage of time, energy and skills generally spent by professionals on correcting maladaptation set in over the passage of time due to poor quality need based services made available to the families.

SOME FURTHER RESEARCH INDICATIONS

Few suggestions for further research are presented below:

- Impact on parents because of having a child with mental retardation has been studied related to a limited number of parent, child and family variables. Nature of impact and its relationship with other factors could be further studied such as coping styles of parents, marital adjustment between parents, cohesion and involvement of various members in the family and other impact related variables such as both parents working, having only one child or more than one child with disability in the family, etc. Such information would help in designing intervention programmes to reduce the negative impact on parents.

- The number of parents reporting positive impact were very few in the study conducted. It would be worthwhile to study such a group of parents and the factors which facilitate positive impact.

- Availability of quality and quantity of support have been reported and seen to be important indices of impact and coping for parents. Supportive factors within joint and extended families which help reduce the impact on the parents can be studied to guide intervention programmes to strengthen and sustain families in India.

- Indepth study could be conducted to investigate the relationships between the presence of "emotional reactions" and "mental worries" or the degree of impact on parents and their physical and mental well being.

- Comparative effectiveness of various individual or group intervention programmes with parents could be studied to mitigate the impact on parents having children with mental retardation.

CONCLUSION

This chapter highlighted the impact and reactions that parents undergo because of having a child with mental retardation. Results indicate that parents' whole life style gets affected, influencing every aspect of their life including their personal and psychological well-being, their careers, their other children,their family life and routines, their relationships with friends, relatives and people in the community. Professionals need to understand the individual needs of each parent in the context to their specific environment and provide individual need based intervention programmes to strengthen the parents in order to constructively contribute in the habilitation programmes of their child with mental retardation.

REFERENCES

Beckman-Bell, P.J.(1981). **Child related stress in families of handicapped children.** Topics in Early Childhood Special Education,1 , 45-53.

Blacher, J. (1984). **Sequential stages of adjustment to the birth of a child with handicaps: Fact or artifact.** Mental Retardation, 22, 55-68.

Bristol, M. (1987). **The home care of children with developmental disabilities. Empirical support for a model of successful family coping with stress.** In S.Landesman, P.M.Vietze, & M.J.Begab (Eds), Living environments and mental retardation. Washington DC: American Association of Mental Deficiency.

Brotherson, M.J. (1985). **Parents self report of future planning and its relationship to family functioning and family stress with sons and daughters who are disabled.** Unpublished doctoral dissertation. The University of Kansas.

Cummings, S.T., Bayley, H.C., & Rie, H.E. (1966). **Effects of the child's deficiency on the mother of mentally retarded, chronically ill, and neurotic children.** American Journal of Orthopsychiatry, 46, 246-255.

Cunningham, C.C. (1979). **Parent Counselling.** In M.Craft (Eds) Tredgold's Mental retardation, 12th edition, Ballier-Trindale, 313-318.

Dunlap, W.R., & Hollingsworth, J.S. (1977). **How does the handicapped child affect the family? Implications for practitioners.** The Family Coordinator, 26(3), 286-293.

Evans, E.C. (1979). **The grief reaction of parents of the retarded and counsellor's role.** Australian Journal of Mental Retardation 4, 8-12.

Featherstone, H. (1980). **A difference in the family. Living with a disabled child.** New York. Basic Books

Gallagher , J.J., Beckman, P., & Cross, A. (1983). **Families of handicapped children: Sources of stress and its amelioration.** Exceptional Children 50(1), 10-19.

Gallagher J.J., Cross, A., & Scharfman, W. (1981). **The father's role.** Journal of Division for Early Childhood, 3, 3-14.

Gath, A. (1977). **The impact of an abnormal child upon the parents.** British Journal of Psychiatry, 130, 405-410.

Goldfarb, L., Brotherson, M.J., Summers, J.A., & Turnbull A.P.(1986). **Meeting the challenge of disability and chronic illness-A family guide.** Baltimore: Paul Brookes Publishing Co.

Gumz, E.J., & Gubrium, J.F.(1972). **Comparative parental perceptions of a mentally retarded child.** American Journal of Mental Deficiency, 77, 175-180.

Ishtiaq, K. (1977). Mentally retarded children: **A socio-psychological study.** New Delhi, Sultan Chand & Company.

Jain, M.C., & Sathyavathi, K., (1969). **A preliminary note on the problems in the families with a mentally retarded child.** Transactions of All India Institute of Mental Health, 9, 23.

Kaslow, S.W., & Cooper, B.(1978). **Family therapy with learning disabled child and his or her family.** Marriage and Family Counselling, 4(1), 41-49.

Londsdale,G. (1978). **Family life with a handicapped child: The parents speak.** Child, Care, Health and Development, 4, 99-120.

Marshak, L.E. & Seligman, M. (1993). **Counselling Persons with Physical Disability.** Austin, Texas: PRO-ED.

McAndrew, I (1976). **Children with a handicap and their families.** Child, Care, Health and Development, 2, 213-237.

Murphy, A.T. (1982). **The family with a handicapped child: A review of literature.** Developmental and Behavioural Pediatrics, 3 (2), 73-82.

Narayan, H.S. (1979). **The impact of mentally retarded children on their families.** M.D. Thesis.

Olshansky, S. (1962). **Chronic sorrow: A response to having a mentally defective child.** Social Casework, 43, 191-194.

Orr, R.R., Cameron, S.J., Dobson, L.A., & Day, D.M. (1993). **Age related changes in stress experienced by families with a child who has developmental delays.** Mental Retardation, 31(3), 171-176.

Peshawaria, R.(1992). **Meeting counselling needs of parents of disabled children.** Samadhan Newsletter, January, 1992, 10-11.

Quine, L. & Paul, J. (1985). **Examining the causes of stress in families with severely mentally handicapped children.** British Journal of Social Work, 15, 501-517.

Reed, E.W. & Reed, S.C. (1965). **Mental Retardation. A family study.** Philadelphia:Saunders.

Roos, P. (1977). **Parents of mentally retarded people.** International Journal of Mental Health, 6(1), 96-119.

Rousso, H. (1984). **Fostering healthy self esteem.** The Exceptional Parent, 12(1), 21-25.

Seligman, M & Meyerson, R. (1982). **Group approaches for parents of exceptional children.** In M.Seligman (Ed.) Group psychotherapy and counselling with special population, (pp 99-116). Baltimore: University Park Press.

Seshadri,M., Varma, V.K., Verma, S.K., & Pershad, D.(1983). **Impact of a mentally handicapped child on the family.** Indian Journal of Mental Retardation, 473-478.

Skrtic, T.M., Summers, J.A., Brotherson, M.J., & Turnbull A.P.(1984). **Severely handicapped children and their brothers and sisters.** In J.Blacher (Ed), Severely handicapped young children and their families (pp 215-246). New York: Academic Press.

Strain, P.S. (1982). **Social development of exceptional children.** Rockville, MD: Aspen Publications.

Summers, J.A. (1987). **Family adjustment:Issues in research on families with developmentally disabled children.** In V.B. Van Hasselt, P.S. Strain, & M. Hersen (Eds), Handbook of developmental disabilities (pp 79-90). New York: Pergamon Press.

Turnbull, A.P. & Turnbull, H.R. (1990). **Families, professional, exceptionality:** A special partnership. Colombus, OH: Charles E.Merrill.

Turnbull, A.P., Summers, J.A., & Brotherson, M.J. (1984). **Working with families with disabled members:** A family system approach. Lawrence: University of Kansas Affiliated Facility.

Wickler, L.(1981). **Chronic stress of families of mentally retarded children.** Family Relations, 30, 281-288.

Wickler, L.(1986). **Periodic stresses in families of children with mental retardation.** American Journal of Mental Deficiency, 90, 703-706.

Vadasy, P.F., Fewell, R.R., Meyer, D.J., Schell, G., & Greenberg, M.T. (1984). **Involved parents:Characteristics and resources of fathers and mothers of young handicapped children.** Journal of the Division for Early Childhood,8, 13-25.

Ventura, J.N., & Boxx, P.G.(1983). **The family coping inventory applied to parents with new babies.** Marriage and the Family, 45, 867-875.

It is not enough to give handicapped life, they must be given a life worth living.

Helen Keller

CHAPTER 3

Assessment of Family Needs: Development of NIMH Family Needs Schedule (NIMH-FAMNS)

INTRODUCTION

Families are the critical agents in the care, management and habilitation of individuals with mental retardation. Parents, siblings and other significant family members are increasingly, being involved in the training and habilitation of individuals with mental retardation. The underlying concept of family centered intervention is that children's functioning can be maximized by providing services that are designed to enhance the effectiveness of their families. Families are interactive, interdependent systems with individual members reciprocally affecting each other (Hornby, 1994; Dunst, Trivette, Deal, 1988). Consequently, any events or changes that affect one member of the family will directly or indirectly affect all other members and therefore affect the family as a whole (Marshak & Seligman, 1993). Research and experience in working with families have repeatedly stressed that unmet needs may not only have negative effects on the health and well being of the family, but also interfere significantly in the implementation of the intervention programme. Thus, to enhance the effectiveness of the family it is important to identify the needs of individual family members, locate resources for meeting those needs and help guide family members in utilising these identified sources. Such a realization has already lead to the amendment of the U.S. Education of Handicapped Act

of 1986 (P.L.99-457). The revisions included as Part H of P.L. 99-457 necessitates by law to develop individualized family service plan (IFSP) for families who have children with developmental delays or those who are at risk for developmental delays. The law includes IFSP only for families having children below 3 years, for reasons best known to the people involved in such decision making. However, the need to have family focussed interventions for individuals with mental retardation across all ages cannot be underestimated. It is precisely the passing of this law that provided the impetus in the United States to develop scientific instruments for family assessment to help provide needed family interventions.

ASSESSMENT OF FAMILY NEEDS

In order to make the services more meaningful for families having children with mental retardation , it is logical that services must match the needs of the service users. Assessment of the family needs thus becomes crucial.Unfortunately, a barrier to effective family assessment is a lack of technically sound functional assessment tools (Bailey & Simeonsson, 1988). Though assessment of families may take into account a number of dimensions such as family needs, family strengths, family styles of coping, family resources, family structure, etc., the present chapter focusses mainly on the review of existing scales to assess family needs (McGrew, Gilman & Johnson, 1992) and development of NIMH-Family Needs Schedule based on both logical and empirical understanding. Such a tool would be considered useful to service providers in both setting intervention goals based on individual needs of different members of the family as also to evaluate the effectiveness of such intervention programmes.

Review of scales to assess family needs

A review of existing literature (both western and Indian) related to the available tools for assessment of needs of families having special children was compiled as one of the initial steps to the development of NIMH-FAMNS. The review of the 15 scales to assess family needs and

sources as presented by McGrew, Gilman & Johnson (1992) in their research paper is reproduced for reader's benefit in the present chapter in Table 3.1.

TABLE 3.1
SCALES TO ASSESS FAMILY NEEDS-DESCRIPTIVE CHARACTERISTICS

Instrument/Source	Number of items[a]	Rating scale	Normative data and scores	Organization/Subareas[b]	
Family Information Preference Inventory **Turnbull & Turnbull(1986)**	37	0-3	No	1. Teaching child at home 2. Advocacy and Working with Professionals 3. Planning for the Future 4. Family Relaxation and Using More Support (Logical)	
Family Needs Scale **Dunst, Trivette & Deal (1988)**	41	1-5	No	1. Basic Resources 2. Specialized Child Care 3. Personal/Family Growth 4. Financial & Medical Resources 5. Child Education/Therapy 6. Meal Preparation & Adapted Equipment 7. Care of Child in Future 8. Household Support (Empirical)	
Family Needs Survey **Bailey, Blasco & Simeonsson (In Press)** **Bailey & Simeonsson (1988a,1988,1985)**	35	1-3	No	1. Needs for Information 2. Needs for Support 3.Explaining to others 4. Community service 5. Financial Needs 6. Family Functioning	1. Information needs 2. Family & Social support 3. Explaining to others 4. Professional support 5. Financial needs 6. Child care (Empirical)
Family Resource Scale (G)[c] and Resource Scale for Teenage Mothers **Dunst & Leet (1987); Dunst, Leet & Trivette (1988); Dunst, Trivette & Deal (1988); Dunst, Vance & Cooper (1988)**	31	1-5	No	1. Growth & Support 2. Health & Necessities 3. Nutrition & Protection 4. Physical Shelter 5. Intrafamily Support 6. Communication 7. Child Care & Employment	
FISC Family Needs Survey **Mc Grew, Gilman & Johnson (1989)** **St.Cloud Community Schools (1989)**	59[d]	1-2 or 1-4	No	None	

Instrument/Source	Number of items[a]	Rating scale	Normative data and scores	Organization/Subareas[b]
How Can We Help ? **Child Development Resources (1989)**	39	3 Cat.	No	1. Information 2. Child Care 3. Community Services 4. Medical & Dental Care 5. Talking about Child 6. Future & Transition Planning (Logical)
Parent Needs Inventory **Fewell, Meyer, Schell & Vadasy (1981)** **Vadasy, Meyer, Fewell & Greenberg (1985)**	75	1-9	No	1. Grief 2. Child Development 3. Local Resources (Logical)
Parent Needs Survey **Seligman & Benjamin - Darling (1989)**	26	3 Cat.	No	None
Parenting stress Index (Parent Domain Scales) (G)[c] **Abidin (1986); Doll (1989); Gresham (1989)**	54[d]	1-5	Parents who visited pediatric clinics in central Virginia (N=534) Total & Subscale Percentiles	1. Depression 2. Attachment 3. Restriction of Role 4. Sense of Competence 5. Social Isolation 6. Relationship with Spouse 7. Parent Health (Logical & Empirical)
Prioritizing Family Needs Scale **Finn & Vadasy (1988); Finn, Vadasy, Snyder & Calamas(1990)**	41	0-6	No	1. Basic Needs 2. Health & Safety 3. Social Needs 4. Personal Needs 5. Needs for Self-Fulfillment (Logical)
Quality of Life-Parent Forum (G)[c] **Olson & Barnes (1985)**	40	1-5	Natl.. random sample from Aid Assoc. for Lutherans (N=1,928) Total Scale Percentiles	1. Marriage & Family life 2. Friends 3. Extended Family 4. Health 5. Home 6. Education 7. Time 8. Religion 9. Employment 10.Mass Media 11.Financial Well being 12.Neighbourhood & Community (Logical) 1. Family Life 2. Family Members 3. Health 4. Home-Physical Space 5. Home-Household Responsibilities 6. Time 7. Religion, Friends & Extended Family 8. Employment 9. Mass Media 10. Financial well being 11. Neighbourhood & Community edn. (Empirical)

Instrument/Source	Number of items[a]	Rating scale	Normative data and scores	Organization/Subareas[b]	
Questionnaire on Resources and stress-Short Form **Donovan (1988); Dyson, Edgar & Crnic (1989) Friedrich, Greenberg & Crnic (1983) Friedrich, Wilturner & Cohen (1985), Scott, Sexton, Thompson & Wood (1989), Seltzer & Krauss (1989); Wood & Flynt (1990)**	52	T/F	No	1. Parent and Family Problems 2. Pessimism 3. Child Characteristics 4. Physical Incapacities (Empirical)	
Support Functions Scales **Dunst, Trivette & Deal (1988)**	20	1-5	No	1. Emotional Support 2. Child Support 3. Financial Support 4. Instrumental Support 5. Agency Support (Empirical)	
Survey for parents of Children with Handicapping Conditions **Moore, Hamerlynck, Barsh, Spicker & Jones(1982)**	75	1-5	No	1.Finances 2. Obtaining Information 3. Communicating with Professionals 4. Eligibility 5. Availability 6. Community Attitudes 7. Time 8. Impact on primary caregiver 9. Limits on Lifestyle & Life Choices 10. Impact on Family (Logical-original Organization)	1. Finance 2. Obtaining information 3. Availability of Services 4. Emotional Impact on Primary Caregiver 5. Role Demands on Primary Caregiver 6. Impact on Family 7. Concern for Child (Logical reorganized scales for scoring)

Source : K.S.McGrew, C.J.Gilman, & S.Johnson (1992). A Review of scales to assess family needs, Journal of Psycho-educational Assessment, 10, 4-25

Note:
[a]Number of items excludes open-ended items or items from instruments that measure other domains.
[b]Subareas are categorized according to whether they are based on logical, rational content analysis (logical) or factor analysis (empirical)
[c](G) indicates that content of items is applicable to the general population. All other scales have items that address needs of families of children with disabilities.
[d]Subset of items from the scale that represents family needs.

Although researchers have used idiosyncratic definition of what family is, the term "family" conjures nostalgic images of a mother, father, two or three children and grandparents living together at home. However, the review of commonly used family assessment scales presented in Table 3.1 indicates that most of the scales/schedules identify the needs of 'parents'

only. It is important to note that siblings and grandparents also form an important part of the family and that they too have their unique needs. Identifying needs is the first step towards meeting needs. To the best of knowledge of the authors, so far there has been no empirical study reported in India nor any instrument developed that can be used to identify the needs of different members of the families having children with mental retardation. The present chapter describes the attempts made in the development of the Family Needs Assessment Schedule (NIMH-FAMNS) to identify the needs of the Indian families having children with mental retardation.

DEVELOPMENT OF FAMILY NEEDS SCHEDULE (NIMH-FAMNS)

NIMH - FAMNS, a semistructtured interview schedule was developed for the following purpose:

1. To identify needs of the families having mentally retarded individuals.
2. To prioritise the needs for family intervention.
3. To objectively evaluate family intervention programmes.

NIMH-FAMNS consists of three schedules

1. NIMH FAMILY NEEDS SCHEDULE (Parents)
2. NIMH FAMILY NEEDS SCHEDULE (Siblings)
3. NIMH FAMILY NEEDS SCHEDULE (Grandparents)

DEVELOPMENT OF NIMH-FAMNS (Parents)

NIMH - FAMNS (Parents) was developed using the following scientific procedures

1. Formation of needs/item pool
2. Selection of items for initial try out.
3. Preparation of NIMH-FAMNS (Parents)
4. Initial tryout and revision
5. Pilot study and revision
6 Final study
7. Reliability and validity

1. Formation of needs/item pool

The initial needs pool of 80 items for the NIMH-FAMNS (Parents) was developed by:

a) Undertaking an exhaustive review of both western and Indian literature available on needs of families having mentally retarded children.

b) NIMH database on questions/queries asked as also needs expressed by parents of children with mental retardation during parent training workshops conducted by NIMH in the last ten years.

c) Professional experiences of first three authors.

2. Selection of items for initial tryout

The initial item pool of 80 items/needs listed in question form were further put through scrutiny and selection. The last three authors of this book were asked to rate each of the 80 items/needs on a three point scale. The score of each item/need on the schedule ranged from 2 (most appropriate need); 1 (less appropriate) and 0 (least appropriate need). The raters were asked to use the following guidelines for rating the items:

a) **Identifying global needs:** Higher rating should be given to items which Indian parents express at different stages in the life cycle of their child with mental retardation belonging to any level of mental retardation .

b) **Indian context** i.e., emphasis to be placed on rating those items higher that were typically relevant to Indian parents given their psycho-socio-cultural environment.

c) **Enhancing family functioning** i.e., emphasis to be placed on rating those items higher , meeting of which were considered useful in strengthening families i.e., enhancing the coping skills of the families having mentally retarded children.

d) **Socio-demographic:** To rate those items higher which would cater to as far as possible the needs of families having children of any age group,

belonging to any socio economic status and living in any geographic area.

By following the above mentioned criteria, items considered 'the most appropriate a need' by the authors/raters were retained and the items rated as 'less appropriate a need' or 'least appropriate a need'were deleted . Hence 20 items got excluded and 60 items got included in the NIMH-FAMNS (Parents).

Few examples of the items which got excluded were:

Do you need information on how to find a job for self?
Do you need information on how to spend your leisure time?

3. Preparation of NIMH - FAMNS (Parents)

a) Area

Eighteen main areas were decided upon by the the first and the third authors under which the 60 selected items /parents needs were to be classified. The 19th area was included as 'others'. Following this, the two authors independently placed each of the 60 items into 18 main areas and percentage of agreement was calculated. 90% of agreement was obtained by the two authors. Discrepancies, however, were sorted out. Language of items was also made simpler. The 18 main areas of parents needs as also the number of items included in each area are given in Table 3.2. It was decided to retain the 'others' area as the 19th one so as to accommodate any other need felt by parents which may not have got covered in the schedule.

TABLE 3.2.
NUMBER OF ITEMS IN DIFFERENT NEEDS AREAS
DURING INITIAL PHASE

Sl.No.	Areas (Needs)	Number of Items
1.	Condition	5
2.	Parent-Child Interaction	5
3.	Resource/Services	4
4.	Residential/Hostel	2
5.	Professional Support	5
6.	Personal - Emotional	3
7.	Personal - Social	3
8.	Support-Physical	5
9.	Intra-family Support	5
10.	Extended Family	3
11.	Friends/Neighbours	2
12.	Marriage Issues	1
13.	Sexuality Issues	1
14.	Financial Needs	2
15.	Government Benefits	1
16.	Vocational Planning	2
17.	Future Planning	6
18.	Advocacy	5
19.	Others	
Total Main areas = 19	Total number of items/needs = 60	

b) Scoring

i) A quantitative scoring system based on the intensity of the need felt was evolved to assign numerical values for each of the parent's response to every item on the schedule. The score of each item on the schedule ranged from 0 (no need); 1 (not sure); 2 (little a need) and 3 (very much a need).

It was considered that greater the score, greater was the need felt.

ii) At the end of each main area provision was made to have total and mean score. At the end of the schedule total parent need score and

mean score was listed. Provision to have a parent profile of needs was also included.

iii) Each item on the schedule also had a time frame factor i.e., whether the need felt by the parent was a present one or was it a future need.

4. Initial try out and revision

The NIMH - FAMNS (Parents) consisting of 60 items was put through an initial tryout with a random sample of 10 families having mentally retarded children at Secunderabad/Hyderabad. The sample included 10 mothers and 9 fathers. Characteristics of the sample are presented in Table 3.3 and Table 3.4.

TABLE 3.3
PARENT CHARACTERISTICS:INITIAL TRYOUT

Sl. No.	Variable	Parent Characteristics		Total (%)	Mean (SD)
1.	Age (Yrs)	< = 50	> 50		
	n	9	10	19	44.5
	(%)	(47.4)	(52.6)	(100)	(9.61)
2.	Sex	Mother	Father		
	n	10	9	19	
	(%)	(52.6)	(47.4)	(100)	
3.	Education	< Degree	Degree +		
	n	10	9	19	
	(%)	(52.6)	(47.4)	(100)	
4.	Income/Month in Rs.	Upto Rs.1000	> Rs.1000		
	n	8	11	19	1300.7
	(%)	(42.1)	(57.9)	(100)	(159.5)

TABLE 3.4
CHARACTERISTICS OF MENTALLY RETARDED INDIVIDUALS: INITIAL TRYOUT

Sl. No.	Variable	Child Characteristics				Total (%)	Mean (S.D)
1.	Age (Yrs)	0-6	7-12	13-18	19+		
	n	2	2	2	4	10	15.68
	(%)	(20)	(20)	(20)	(40)	(100)	(9.51)
2.	Sex	Male		Female			
	n	6		4		10	
	(%)	(60)		(40)		(100)	
3.	Severity	Mild	Moderate	Severe			
	n	2	5	3		10	
	(%)	(20)	(50)	(30)		(100)	

The first and third authors conducted the interviews using the NIMH-FAMNS (Parents). All interviews were tape recorded with

permission from the parents. These were later transcribed and coded by the interviewer. The results are shown in the Table 3.5 given below which indicated the practical feasibility of the NIMH-FAMNS (Parents).

TABLE 3.5
PERCENTAGE ENDORSEMENT OF NEEDS AREAS DURING INITIAL TRY OUT

Sl.No.	Areas/ (Needs)	Percentage Endorsement (N=19)
1.	Condition	73.6
2.	Parent-Child Interaction	68.4
3.	Resource/Services	73.6
4.	Residential/Hostel ,	47.3
5.	Professional Support	47.3
6.	Personal - Emotional	31.5
7.	Personal - Social	52.6
8.	Support-Physical	42.1
9.	Intra-family Support	21.1
10.	Extended Family	21.1
11.	Friends/Neighbours	42.1
12.	Marriage Issues	57.8
13.	Sexuality Issues	63.1
14.	Financial Needs	78.9
15.	Government Benefits	94.7
16.	Vocational Planning	78.9
17.	Future Planning	73.6
18.	Advocacy	47.3
19.	Others	57.9

During this initial tryout each parent interviewed was asked for a general and specific feedback about the NIMH-FAMNS (Parents) using various questions such as :

a) *How did you like being asked specific questions in the interview session?*
b) *Do you think the interviewers asked all relevant questions related to your needs ?*
c) *How did you find the language used while the questions were asked?*
d) *Do you have any suggestions to offer in the use of this particular schedule used with you to elicit information on your needs because of having a mentally retarded child in the family?*

Feedback obtained from parents as also the observations of the interviewers are presented below :

i) Parents reported that some of the items asked sounded repetitive in nature. Items in the category of intra-family support, extended support, support from friends and neighbours needed to be clubbed together under one question rather than being spread in the interview schedule as seperate items.

ii) 57.9% of parents during the interview did identify needs in the 'others' category which were related to family hence the need was felt to have on additional category. The rest of the parents felt that the questions asked covered all their needs.

iii) Parents needed clarity on few items reflecting the need to revise the language further.

iv) All parents felt happy that they were being asked about their needs/concerns in such an exhaustive way for the first time ever.

v) The time frame factor in the interview schedule i.e., asking parents on each item whether it was their present felt need or future need, led to confusion in many parents. Majority of the parents said that it was difficult to talk about the future need now.

vi) Parents were seen to rate their needs by using the categories such as 'very much a need' 'little a need' or 'not a need'. None of the parents were found to use the category 'not sure a need'.

The following revision of NIMH-FAMNS was carried out after the initial try out.

i) Some of the items were added, clubbed and deleted. Sentence structure was altered and rearranged for some items. Items were resequenced. Language of some of the items was made simpler. The revised version of NIMH-FAMNS (Parents) resulted in 45 items.

ii) The 18 areas + one 'others' category were reorganised. The revised version had 15 areas.

iii) The new categories added were namely: a)'Facilitating interaction' which was formed by combining old categories such as intrafamily support, extended family and friends/neighbours, b) 'Family relationships' which was based on the family needs expressed by parents in the 'others' category.

iv) The time frame factor, i.e, asking whether the particular need was a present felt need or future need was dropped. Instead a remarks column was added to have provision to note such comments by parents if made voluntarily by them during the interviews.

v) The category of scoring "Not sure a need" was dropped. Hence 3 out of the original 4 categories were retained. "Very much a need" was given a score of 2, "little a need" score 1 and "not a need" a score of 0.

vi) Guidelines for administration of NIMH-FAMNS (Parents) were framed.

Revised version of need areas of NIMH-FAMNS (Parents) following initial try out with 10 families having children with mental retardation is given in Table 3.6.

TABLE 3.6
NUMBER OF NEED ITEMS AFTER INITIAL TRYOUT

Sl.No.	Areas (Needs)	Number of Items
1.	Information-Condition	6
2.	Child Management	7
3.	Facilitating Interaction	2
4.	Services	5
5.	Hostel	2
6.	Personal-Social	5
7.	Personal-Emotional	2
8.	Support-Physical	3
9.	Marriage	1
10.	Sexuality	1
11.	Financial	3
12.	Government Benefits and Legislation	2
13.	Vocational Planning	1
14.	Future Planning	3
15.	Family Relationships	2
Total Main areas = 15		Total number of items/needs = 45

5. Pilot Study

The pilot study was conducted by the first, third and fourth authors and two research assistants specially appointed for collection of data. Both the research assistants had completed their M. Phil in psychology and were well versed with interview techniques. However, before the pilot study two 4-hours training sessions was undertaken by the first and third authors with the research assistants. The fourth author also was part of the team. During these two sessions details of the study and interview techniques needed to be used was discussed. Simulated exercises were conducted between the team members to help clarify issues related to eliciting information from parents in the most objective way using NIMH-FAMNS. Administration and scoring issues and any further clarifications sought by research assistants were clarified. The pilot study was conducted on a random sample of 20 families i.e., which included 20 mothers and 19 fathers (see Table 3.7 & Table 3.8) having mentally retarded children from the twin cities of Secunderabad/Hyderabad.

TABLE 3.7

PARENTS CHARACTERISTICS:PILOT STUDY

Sl. No.	Variable	Parent Characteristics			Total (%)	Mean (S.D)
1.	Age (Yrs.) n (%)	< = 35 12 (30.7)	36-50 14 (36.0)	> 50 13 (33.3)	39 (100)	44.4 (10.2)
2.	Sex n (%)	Mother 20 (51.2)		Father 19 (48.8)	39 (100)	
3.	Education n (%)	Primary 10 (26.6)	Sec-Inter 10 (25.6)	Degree 19 (48.8)	39 (100)	

TABLE 3.8

CHARACTERISTICS OF MENTALLY RETARDED INDIVIDUALS: PILOT STUDY

Sl. No.	Variable	Child Characteristics				Total (%)	Mean (SD)
1.	Age (Yrs) n (%)	0-6 5 (25)	7-12 5 (25)	13-18 5 (25)	19+ 5 (25)	20 (200)	14.37 (7.25)
2.	Sex n (%)	Male 12 (60)		Female 8 (40)		20 (100)	
3.	Severity n (%)	Mild 5 (25)	Moderate 10 (50)	Severe 5 (25)		20 (100)	

To obtain a feedback parents were asked the same questions as asked earlier above during the initial try out phase after the completion of the NIMH-FAMNS (Parents) to obtain feedback. None of the parents, this time presented any new suggestions to NIMH-FAMNS (Parents). All the parents expressed their satisfaction related to content, structure and language of the NIMH-FAMNS (Parents). During pilot study none of the parents reported any extra need in the 'others' category. For identification of needs purposes any of the two ratings such as 'very much a need' or 'little a need' was considered as endorsed need. Results in terms of endorsement percentage by parents in each of the areas during the pilot study are presented in Table 3.9.

TABLE 3.9
PERCENTAGE ENDORSEMENT OF NEED AREAS BY PARENTS DURING PILOT STUDY

Sl.No.	Area/Needs	Percentage Endorsement(N=39)
1.	Information-Condition	76.9
2.	Child Management	69.2
3.	Facilitating Interaction	61.5
4.	Services	79.5
5.	Hostel	43.5
6.	Personal-Social	17.9
7.	Personal-Emotional	46.1
8.	Support-Physical	46.1
9.	Marriage	51.2
10.	Sexuality	56.4
11.	Financial	74.3
12.	Government Benefits & Legislation	97.4
13.	Vocational Planning	46.1
14.	Future Planning	94.9
15.	Family Relationships	38.5

Observations from the pilot study indicated the need to rearrange the sequence of areas included in NIMH-FAMNS (Parents) to have better flow of gathering information. The 'others' category was still retained even though none of the parents endorsed any need in this category. After incorporating the above changes the final version of NIMH-FAMNS (Parents) had 45 items/needs under 15 domains plus 'others' category.

6. Final study

The final study included a sample of 120 families i.e., 218 parents including 115 mothers and 103 fathers of mentally retarded children. The sample characteristics are given in Table 3.10 and Table 3.11. Being a multicentered study the sample was drawn from three centres catering to services in three cities in the country i.e., Balavikas Institute, Thiruvananthapuram (South India), Navjyoti Centre, Delhi (North India) and Digdarshika Institute, Bhopal (Central India). Purposive sampling based on pre-determined criteria was used to include families. The procedure for drawing sample of 120 families from three centres has already been described in Chapter 2.

Each centre pooled data pertaining to 40 families having mentally retarded children from birth to 6 years, 7 to 12 years, 13 to 18 years and 19 years and above.

TABLE 3.10
PARENT CHARACTERISTICS: FINAL STUDY

Sl. No.	Variable	Parent Characteristics			Total (%)	Mean (S.D)
1.	Age(Yrs.) n (%)	< =35 63 (28.9)	36-50 122 (55.9)	>50 33 (15.2)	218 (100)	41.5 (8.91)
2.	Sex n (%)	Mother 115 (52.7)		Father 103 (47.3)	218 (100)	
3.	Education n (%)	Primary 36 (16.5)	Sec-Inter 75 (34.4)	Degree 107 (49.1)	218 (100)	
4.	Income/ Month (In Rs.) n (%)	< =1000 100 (45.9)		> 1000 118 (54.1)	218 (100)	3242.7 (2591.5)

TABLE 3.11
CHARACTERISTICS OF MENTALLY RETARDED INDIVIDUALS : FINAL STUDY

Sl. No.	Variable	Child Characteristics Frequecies				Total (%)	Mean (SD)
1.	Age(Yrs) n (%)	0-6 30 (25)	7-12 30 (25)	13-18 30 (25)	19 + 30 (25)	120 (100)	13.10 (7.51)
2.	Sex n (%)	Male 84 (70)		Female 36 (30)		120 (100)	
3.	Severity n (%)	Mild 33 (27.5)	Moderate 58 (48.3)	Severe 29 (24.2)		120 (100)	
4.	Services n (%)	Attending 83 (69.2)		Dropouts 37 (30.8)		120 (100)	

For identification of needs any of the two ratings obtained by the parents on a given need such as "Very much a need" or " Little a need" were considered as an endorsed need. Percentage endorsement given by 218 parents on each of the 45 items/needs included under 15 areas of NIMH-FAMNS are given in Table 3.12. Each of the items has been abbreviated to represent the need expressed by the parents.

TABLE 3.12
PERCENTAGE ENDORSEMENT OF NEEDS EXPERIENCED BY PARENTS IN THE FINAL STUDY

Sl.No.	Areas/Needs	Endorsement Percentage (N=218)
1.	**Information-Condition**	**86.9%**
	1. Disability Condition	85.8
	2. Assessment Reports	87.2
	3. Expected Achievement	95.4
	4. Adverse Sequelae	90.8
	5. Reading Material	89.9
	6. Nutrition	72.0
2.	**Child Management**	**75.6%**
	7. Child Development	41.3
	8. Child Rearing	87.6
	9. Discipline	87.6
	10. Problem Behaviours	90.4
	11. Child Cooperation	72.5
	12. Child Training	76.6
	13. Parent-Teacher Interaction	73.4
	14. Plan another child	18.8

Sl.No.	Areas/Needs	Endorsement Percentage (N=218)
3.	**Facilitating Interaction**	58.3%
	15. Explain: Child's Condition	57.3
	16. Family Involvement	59.2
4.	**Services**	**83.6%**
	17. Services Available	87.6
	18. Decision Making: School	83.9
	19. Training Materials	92.7
	20. Home Training	84.9
	21. Regular /Special School Effects	68.8
5.	**Vocational Planning**	**89.0%**
	22. Vocational Rehabilitation	89.0
6.	**Sexuality**	**78.9%**
	23. Child sexuality	78.9
7.	**Marriage**	**66.5%**
	24. Marriage of child	66.5
8.	**Hostel**	**48.0%**
	25. Decision Making: Hostel	45.0
	26. Nature of Hostel	50.9
9.	**Personal-Emotional**	**39.7%**
	27. Time to self	49.1
	28. Talk about personal problems	49.1
	29. Help when sad or depressed	56.4
	30. Physical health problem	25.2
10.	**Personal-Social**	**72.7%**
	31. Discussion with friends	72.0
	32. Discussion with parents	73.4
11.	**Support-Physical**	**55.0%**
	33. Transport for child	73.4
	34. Manual support for transportation	57.6
	35. Domestic support for child care	33.9
12.	**Financial**	**64.7%**
	36. Financial help : services	72.5
	37. Financial help : training material	71.1
	38. Financial help : others	50.5
13.	**Family Relationships**	**50.5%**
	39. Family problems	28.0
	40. Impact on other child	72.9
14.	**Future Planning**	**84.4%**
	41. Financial Planning:Future	85.3
	42. Inheritanace:Property	82.1
	43. Financial Planning : Social Security	85.8
15.	**Government Benefits & Legislation**	**93.6%**
	44. Government Benefits	95.4
	45. Legislation	91.7

b. Preparation of NIMH-FAMNS (Grandparents)

Questions representing 20 need items (see Table 3.21) expressing grandparent needs were framed. A 3 point scoring system to help quantify the responses was used. Each item was given a score of 2 if the item/need was expressed as 'very much a need', a score of 1 if the need was expressed as 'little a need' and a score of 0 if it was expressed as 'no need'.

c. Pilot study of NIMH-FAMNS (Grandparents)

The 20 item needs schedule including an open ended question on 'any other need' was administered on 10 grandparents having children with mental retardation. Sample characteristics of grandparents having grandchildren with mental retardation are presented in Table 3.22. Results of the pilot trial of NIMH-FAMNS (Grandparents) are presented in Table 3.23.

TABLE 3.22
DEMOGRAPHIC INFORMATION ABOUT GRANDPARENTS DURING PILOT STUDY

Sl. No.	Variable	Grandparent Characteristics		Total (%)	Mean (S.D)
1.	Age (Yrs.) n %	<65 5 (50)	> =65 5 (50)	10 (100)	69.0 (612)
2.	Sex n %	Grandmother 7 (50)	Grandfather 3 (30)	10 (100)	
3.	Education	< =Secondary 4 (40)	College 6 (60)	10 (100)	
3.	Physical Health Problems	Present 2 (20)	Absent 8 (80)	10 (100)	

TABLE 3.23
PERCENTAGE ENDORSEMENT OF NEEDS EXPRESSED BY GRAND PARENTS DURING PILOT STUDY

Sl.No.	Needs/Items	Percentage Endorsement (N=10)
1.	Information-Condition	80
2.	Expected Achievement	70
3.	Information : Services	80
4.	Information:Child management	20
5.	Guidance : Help family	30
6.	Information : Government benefits	70
7.	Training : Communication	100
8.	Cause : Mental Retardation	80
9.	Sensitivity : Professionals	40
10.	Help: When sad	20
11.	More time : Self	20
12.	Financial Help	30
13.	Help : Future planning for family members	20
14.	Information : Hostel Placement	30
15.	More time with children	60
16.	More time for religious activities	10
17.	Help : Explain condition	30
18.	Sexuality issues related to grandchild	10
19.	Marriage issues related to grandchild	10
20.	Effects of admitting grandchild to normal school/ special school	10

Following this pilot study and feedback from grandparents and interviewers, revisions were carried out in the following aspects:

- Language of items was modified e.g 'mediate conflicts' changed to "resolve conflicts".
- Certain items were reported to be repetitive hence clubbed under one category.

Few items were added as these were reported in"others" category and endorsed by more than 50 % of the grandparents such as their own children i.e., parents of mentally retarded should spend time with them. The revised version had 15 items. 'others' item was retained besides 15 need items for the final tryout.

d. Final study of NIMH-FAMNS (Grandparents)

The revised version of 15 need items with additional item on 'others' was administered to 10 grandparents. Characteristics of the sample are given in Table 3.24.

TABLE 3.24
GRANDPARENT DEMOGRAPHIC INFORMATION :FINAL STUDY

Sl. No.	Variable	Grandparent Characteristics		Total (%)	Mean (S.D)
1.	Age(Yrs.)	< 65	> = 65		
	n	6	4	10	72.0
	(%)	(60)	(40)	(100)	(7.24)
2.	Sex	G.Mother	G.Father		
	n	5	5	10	
	(%)	(50)	(50)	(100)	
3.	Education	< = Secondary	College		
	n	3	7	10	
	(%)	(30)	(70)	(100)	
4.	Physical Health Problems n	Present	Absent		
		3	7	10	
	(%)	(30)	(70)	(100)	

TABLE 3.25
PERCENTAGE ENDORSEMENT OF NEED ITEMS BY GRANDPARENTS DURING FINAL STUDY

Sl.No.	Needs/Items	Percentage Endorsement
1.	Information : Condition	80
2.	Expected Achievement	60
3.	Information : Resources	90
4.	Information : Child Management	40
5.	Guidance : Help family	40
6.	Help: When sad	50
7.	More time : Children	70
8.	Help : Grandchild	60
9.	More time: Self	50
10.	Financial Help	60
11.	Cooperation: Professionals	40
12.	Help: Resolve family conflicts	30
13.	Help : Future planning (family members)	60
14.	Help: Hostel placement	20
15.	Information : Govt. benefits	90

The endorsement rates on each need item of NIMH-FAMNS (Grandparents) are presented in Table 3.25. For identification of needs, any of the two ratings obtained by grandparents on a given need such as 'very

much a need' or 'little a need' was considered as an endorsed need. During the final tryout no new need was expressed by the grandparents. Hence the 'others' category was deleted from the final version of NIMH-FAMNS (Grandparents).

The final version of NIMH-FAMNS (Grandparents) has 15 needs/items (See Chapter 8). The present schedule is relevant from aspects of collecting reliable information on the diverse needs of Indian grandparents.

5. Reliability and Validity

Reliability of NIMH- FAMNS (Grandparents) was computed through establishing inter-rater agreement between first and third author for the responses obtained from 10 grandparents. Both the raters independently classified each of the responses of grandparents to the three questions asked into identified categories related to support provided, impact and needs of grandparents due to having a grandchild with mental retardation. The inter-rater agreement percentages obtained was as follows:

Support: 97.3% ; Impact: 98.0%; Needs: 95.3%

Concurrent Validity of NIMH-FAMNS (Grandparents) was established on 10 grandparents included in the final study by comparing the reported needs of grandparents obtained from (i) use of open-ended question, and (ii) comparing with responses from NIMH-FAMNS (Grandparents).

Before administering NIMH-FAMNS (Grandparents) during the final study, each grandparent was asked the following open ended question to elicit information on his/her needs.

"*What are your needs because of having a grandchild with mental retardation in the family*"?

The responses of grandparents to open ended question were classified under different areas and compared with the responses obtained using the NIMH-FAMNS (Grandparents) with the same sample of parents. The findings establish the concurrent validity of NIMH-FAMNS (Grandparents) as there was no need that was expressed by parents using the open ended questionnaire format which was not included in NIMH-FAMNS

(Grandparents). A significant observation however noted was that grandparents endorsed greater number of needs when a structured format like NIMH-FAMNS (Grandparents) was used than when just one open ended question was asked. Probably because grandparents tend to miss out, overlook or not recognize their needs fully when only an open ended question is used. Use of NIMH-FAMNS (Grandparents) gave grandparents an opportunity to scan through all the needs and hence endorsement was higher.

Content Validity of NIMH-FAMNS (Grandparents) was established with 10 grandparents of mentally retarded children (For sample characteristics see Table 3.24) . The endorsement rates on 15 items/needs included in NIMH-FAMNS(Grandparents) are presented in Table 3.25. Bailey and Simeonsson, (1988) followed the criteria of minimum 10 % endorsement for an item to be considered a need. For NIMH-FAMNS (Grandparents) as seen in Table 3.25, the minimum endorsement of any of the need item was 20% which justifies the content validity of the schedule. The content validity is further established because of the fact that none of the grandparents (N = 10) during the final study reported any additional needs in the 'Others' area included in the schedule.

Face Validity: 20 professionals actively working with the families in the field of mental retardation were given NIMH-FAMNS (Grandparents) to rate each of the 15 items/needs included in the schedule whether it is a felt need of the grandparents having mentally retarded grandchildren or not. All the 15 needs were endorsed as felt needs by all 20 professionals.

REFERENCES

J.Bailey, D., & Simeonsson R. (1988). **Family assessment in early intervention.** Colombus, OH: Charles E.Merrill.

Dunst, C.J., Trivette, C.M. & Deal, A.G. (1988). **Enabling and Empowering Families.** Cambridge, MA: Brookline Books.

Hornby, G. (1994). **Counselling in child disability.** London, Chapman & Hall.

Marshak, L.E. & Seligman, M. (1993). **Counselling Persons with Physical Disability.** Austin, Texas: PRO-ED.

McGrew, K.S., Gilman, C.J., & Johnson, S.(1992). **Review of scales to assess family needs.** Journal of Psycho-Educational Assessment (10), pp 4-25.

To be what we are, and to become what we are capable of becoming, is the only end of life.

Robert Louis Stevenson

No finer aim can man attain than to alleviate another's pain.

Alexander Pope

CHAPTER 4

Parents : Needs

INTRODUCTION

The presence of a child with mental retardation in the family calls for a lot of adjustment on the part of the parents and the family members (Peshawaria & Menon, 1991). Some families cope better with the situation than others. Research and experience has indicated that approaches which focus on meeting needs of all members of the family are more effective in helping the family to cope with the situation than approaches that focus only on the child with mental retardation. Identifying and supporting the parents in their efforts to meet the needs of all the family members (including themselves) is one of the most efficient ways of developing parental skills which can enhance the development of all family members. Research has also indicated that greater the number of unmet needs, greater are the number of emotional and physical problems reported by the parents (Dunst & Leet, 1987; Dunst, Vance & Cooper, 1986).

Understanding how the nature of needs of parents having children with mental retardation change over time would enable service providers to provide appropriate support services to each family member. So far there has been no such study in India that has analysed the needs of the parents having a child with mental retardation on his/her family using a life cycle approach. The present study was undertaken to analyze the needs of the parents having children with mental retardation.

CONCEPTUAL FRAMEWORK

The child with mental retardation creates additional needs for parents. A need is something that is desired or lacking but wanted or required to achieve a goal or attain a particular end. Parents of children with mental retardation have continually expressed the need for seeking information regarding therapeutic, educational and vocational programmes. Research has indicated that greater the number of needs unrelated to child-level interventions, greater was the probability that parents revealed that they didn't have the time, energy, or personal investment to carry out the intervention prescribed for their child (Dunst & Leet, 1987; Dunst, Vance & Cooper, 1986). Thus, assessing family needs as perceived by the family should be the first step in providing family directed interventions. Addressing family needs at the outset will lead to greater benefits for the child (Bailey, 1987).

For many years, goals for families with children who have mental retardation were determined solely by professionals based on their own assessment of family needs. There had been limited attempt to directly assess the family needs. Results of recent studies suggest that parents are very much aware of their needs for child rearing information (Bailey, Blasco & Simeonsson, 1992; Bailey & Simeonsson, 1988). Drew, Logan and Hardman (1984) reported that parents expressed needs relating to information about diagnosis, future planning of the child with handicap, medical and financial help. Beveridge (1982) reported that common needs expressed by parents were information on diagnosis and prognosis, future planning, aids and appliances, community resources and training technology to facilitate child development. Shea and Bauer (1985) suggested that needs of parents pertained to information on diagnosis, constructive professional counselling, vocational concerns , financial help and future planning of the child with mental retardation. Meyer (1985) reported that needs of fathers across the lifespan included information on diagnosis and prognosis and family counselling. Roberts (1985) reported mothers expressed needs pertaining to information on diagnosis and prognosis, seeking information on the various services and the future of the child with disability. Identification of community resources, day care services, training the child, initiation of self help groups and respite care were the needs expressed by parents of children with mental retardation (Blackard & Barsh, 1982). In a

survey of seven categories of needs (e.g.,financial, information, family and social support) Bailey, Blasco & Simeonsson (1992), reported that most prevalent needs were on information, selected areas of financial help and opportunity to meet other parents. Mothers expressed significantly more needs than fathers in the area of family and social support, explaining to others and child care. Bailey (1988) reported that the most important needs expressed by parents were teaching their child, respite care help, finding more time for themselves, financial needs and future of the child with disability. Whitehead, Deiner & Taccafordi (1990) reported that the most common needs expressed by parents were information on teaching the child, help in locating respite care, more time for self, future services, available community resources and information on prognosis and diagnosis. Boone et al., (1990) reported that major needs raised by the family were respite care, high caretaking demands, child's communication, training in self-help area and transportation/ access to services. Gowen, Christy & Sparling (1993)in their survey reported that parents expressed need for information on dealing with emotional and time demands of parenting, identifying community resources, planning their child's future and understanding their child's legal rights. Garshelis and McConnell (1993) reported that mothers' most frequently cited needs were for more information on present and future services, more reading materials about how other mothers cope, more time for themselves and help in locating a babysitter.

Peshawaria, Venkatesan and Menon (1988) analysed the consumer demand of services and reported that the needs for training in communication, management of behaviour problems and training in self help area were the most important needs expressed by parents for which they seek out services. Peshawaria & Menon (1991) also reported that the main needs of parents because of having a child with mental handicap included communication of diagnosis, parental and family adjustment, information on government benefits, future of the child, accessibility to formal and informal support and parent training programmes.

The present research was an attempt to study the perceived needs of parents because of having children with mental retardation.

METHOD

Sample

The sample included 218 parents drawn from 120 families of 120 children with mental retardation, comprising of 103 fathers and 115 mothers. The mean age of the sample was 41.5 years (SD = 8.91). 49.1% of the subjects had completed education of degree and above, 50.9 % of the sample had education below degree. The mean family income of the sample per month was Rs 3242.70 (SD = 2591.5). 98 families were nuclear, and 22 were non-nuclear families, while 79 families were living in urban areas, 41 families were living in rural and slum areas.

The mean chronological age of individuals with mental retardation was 13.10 years (SD = 7.51). Of the 120 individuals, 84 (70%) were male and 36 (30%) were female. 27.3 % had mild mental retardation (I.Q = 50-69), 48.3% had moderate mental retardation (I.Q = 35- 49), and 24.2% had severe to profound mental retardation (I.Q < 35). Detailed informaton on sample selection is given in chapter 2.

Procedure

All the interviews were conducted by the research staff in the homes of the subjects included in the study. All the 103 fathers and 115 mothers were interviewed individually. The research staff included the research officer and three research assistants who were M.Phil level psychologists. All of them had received prior training on interview techniques.

Instruments

A semi-structured interview schedule NIMH-FAMNS (Parents) was developed to elicit the needs of parents having children with mental retardation. Development and scoring of the tool are given in chapter 3. Each of the 218 parents were interviewed individually. Each interview lasted about 20-30 minutes depending upon how elaborate the respondent was. All the interviews were tape recorded with prior permission. Descriptive statistics (percentages) and chi-square tests were used to analyze and compare the needs with regard to (i) Index child variables of age, sex, severity of mental retardation and presence of behaviour problems; (ii) Parent variables of sex, age and education; (iii)

Family variables of family income, nature of family (non-nuclear/ nuclear) and area of residence (urban/non-urban).

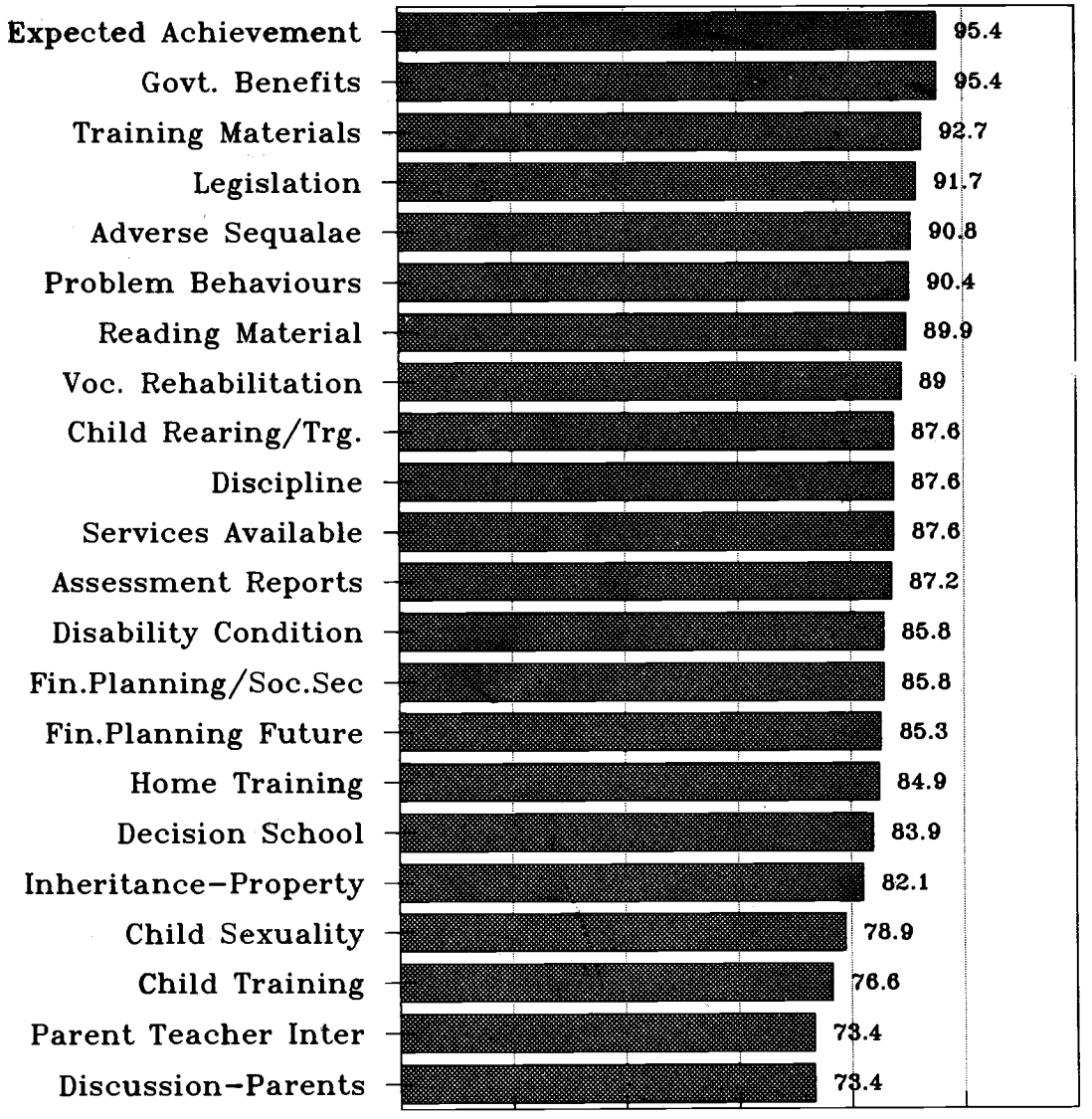
FINDINGS AND OBSERVATIONS

The frequency distribution in percentages and rank order of the perceived needs of parents is presented in Fig 4.1; while area wise needs are given in Table 4.1.

TABLE 4.1

AREA WISE RANKING OF PARENTAL NEEDS ON NIMH FAMNS (Parents)

Sl.No.	Needs/Items	Percentage Endorsement
1.	Government benefits/Legislation	93.6%
2.	Vocational Planning	89.0%
3.	Information - Condition	86.9%
4.	Future Planning	84.4%
5.	Services	83.6%
6.	Sexuality	78.9%
7.	Child Management	75.6%
8.	Personal - Social	72.7%
9.	Marriage	66.5%
10.	Financial	64.7%
11.	Facilitating interaction	58.3%
12.	Support - Physical	55.0%
13.	Family Relationships	50.5%
14.	Hostel	48.0%
15.	Personal - emotional	39.0%



(Fig. 4.1 Contd..)

Fig. 4.1
PERCENTAGE ENDORSEMENT OF NEEDS
BY PARENTS ON NIMH-FAMNS(Parents)

(Contd..)

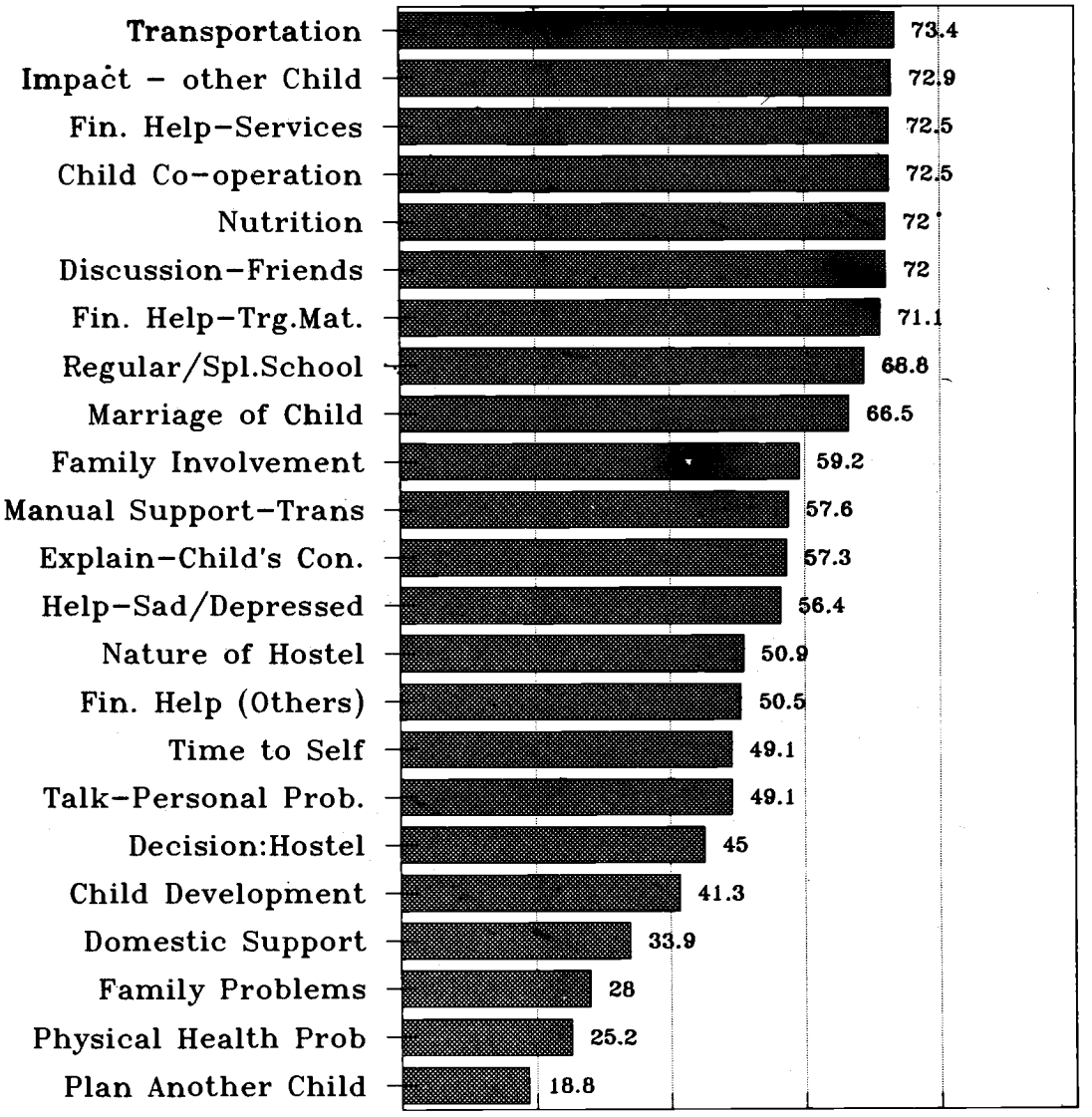


Fig. 4.1 (Contd..)
PERCENTAGE ENDORSEMENT OF NEEDS
BY PARENTS ON NIMH–FAMNS(Parents)

Area wise needs presented in the Table 4.1 indicate that parents reported major needs in knowing what the Government was doing for the mentally retarded individuals and the families. Getting information on "Government benefits/legislation" was the first ranked area/need expressed by 93.6% of the parents followed by "Vocational planning", "Information-condition" of their child, "Future planning" and information on "Services" for training the child, etc. This clearly reflects the general priority of needs of parents whereby the concerns are more related to both the present and future life of their mentally retarded child. The minimum endorsement of needs by parents in a given area was 39% i.e. in personal-emotional. The needs related to "Financial", "Support-physical" or "Hostel" though expressed by some of the parents, do not however figure as front rank needs. Parents though reported "emotional reactions" as the greatest impact (see chapter 2) they have expressed "Personal-emotional" as the lowest ranked need for themselves. It is quite true for Indian parents that the child's needs are given priority over their own needs which is aptly reflected in the results of this study. Also, possible is the question related to the 'parental perception of the need' and possibilities of 'need fulfillment'. Redressal of needs related to personal-emotional aspects is not fully recognised. Such concerns if and when identified are generally attended to, by the available family supports rather than through seeking professional help. Also, seeking professional help to promote mental health is largely considered as a sign of incompetence or a taboo. Few persons who are willing to seek such help find it costly in terms of time and money.

Analysing the first five ranked needs out of a pool of 45 needs as shown in Fig. 4.1, it is noted that parents are highly concerned to know about the prognosis of their child's condition. "Expected achievement" alongwith information on "Government benefits" is the first ranked need expressed by parents followed by other needs such as "Training materials", "Legislation", "Adverse Sequalae" and "Problem behaviours".

The nature of needs expressed by parents were analysed, on three variables related to parents namely age, sex and education level, three variables related to child, i.e., age, sex, severity of mental retardation and three variables related

to family, such as family income, type of family: nuclear/non-nuclear and area of residence: urban/non-urban.

Parent Variables

The analyses of parent needs related to **parent variables** are presented in Table 4.2. On comparing the needs expressed by mothers and fathers of mentally retarded children, mothers reported significantly greater need for information on "services available", "legislation" and in "personal-emotional" area which included especially the need to "Talk about personal problems" and "Help when sad or depressed". No other need was found to be significantly different between fathers and the mothers. However, on comparing the percentage endorsement of needs, mothers had endorsed greater needs than the fathers in all areas except in the area of "Hostel". Though it is difficult to generalise, yet mothers expressing greater needs could be an indication of greater involvement of mothers with the child. Mothers generally being home bound and with extended direct contact with their mentally retarded child have greater chances of feeling isolated. No wonder the need for "Talk about personal problems" and "Help when sad or depressed" have been expressed significantly higher by mothers.

Parents below the age of 35 years reported significantly greater needs such as information on "Reading materials", "Child development", "Services available" and greater help in "Child cooperation". Parents between the age of 36 to 50 years reported significantly greater needs related to getting information on "Child training by teacher" and help in "Home training". Parents above 50 years of age reported significantly greater need for getting information on "Inheritance-property". The results are quite in line with the expected life cycle needs. Younger parents are seen to be searching for greater help in understanding the child's condition, his/her development and possibilities for services, probably still tuning themselves to face hard realities of child training which they come more face to face during their middle ages. Older parents look for greater social securities and management of adolescent and adult related problems of their mentally retarded children.

TABLE 4.2
PERCENTAGE ENDORSEMENT OF PARENTS NEEDS : PARENT VARIABLES

PARENT NEEDS	PARENT EDUCATION			PARENT SEX		PARENT AGE		
AREAS/NEEDS	PRIMARY (n=36)	SEC-INT (n=75)	DEGREE+ (n=107)	FEMALE (n=115)	MALE (n=103)	<=35YR (n=63)	36-50YR (n=122)	> 50YR (n=33)
I. INFORMATION NEEDS	95.37	92.00	80.35*	88.55	84.92	90.50	86.47	81.28
1. Disability Condition	100.00	92.00	76.60***	86.10	85.40	90.50	86.10	75.80
2. Assessment Reports	97.20	93.30	79.40***	88.20	85.40	90.50	86.10	84.80
3. Expected achievement	100.00	100.00	90.70***	97.40	93.20	93.70	95.80	97.00
4. Adverse sequelae	97.20	96.00	85.00**	93.00	88.30	93.70	89.30	90.90
5. Reading material	88.90	90.70	89.70	91.30	88.30	95.20	90.20	78.60*
6. Nutrition	88.90	80.00	60.70***	74.80	68.90	79.40	71.30	60.60
II. CHILD MANAGEMENT	82.13	78.66	71.30	77.26	73.79	78.93	75.64	69.27
7. Child rearing	97.20	93.30	80.40**	88.70	86.40	92.10	87.70	78.80
8. Discipline	97.20	92.00	81.30*	91.30	83.50	92.10	86.90	81.80
9. Problem behaviours	94.40	93.30	86.90	90.40	90.30	89.90	92.60	84.80
10. Child Cooperation	77.80	74.70	69.20	73.90	70.90	87.30	68.90	57.60***
11. Child training	72.20	77.30	77.60	79.10	73.80	66.70	83.60	69.70*
12. Parent - Teacher interaction	75.00	77.30	70.10	77.40	68.90	65.10	77.00	75.80
13. Child development	61.10	42.70	33.60**	40.00	42.70	60.30	32.80	36.40**
III. FACILITATING INTERACTION	69.45	61.35	52.35	60.85	55.30	64.30	60.25	39.40
14. Explanation of child's condition	75.00	58.70	50.50*	59.10	55.30	65.10	59.80	33.30*
15. Family involvement	63.90	64.00	54.20	62.60	55.30	63.50	60.70	45.50
IV. SERVICES	91.10	84.26	80.56	85.40	81.56	88.58	84.92	69.08*
16. Services available	97.20	90.70	82.20*	92.20	82.50*	95.20	86.90	75.80*
17. Decision making school	88.90	89.30	78.50	86.10	81.60	85.70	84.40	78.80
18. Training materials	94.40	93.30	91.60	91.30	94.20	93.70	94.30	84.80
19. Home training	88.90	80.00	86.90	83.50	86.40	87.30	89.30	63.60***
20. Regular / special school effects	86.10	68.00	63.60*	73.90	63.10	81.00	69.70	42.40***
V. HOSTEL	66.70	51.35	39.25**	46.10	50.00	47.60	45.50	57.55
21. Decision making hostel	66.70	46.70	36.40**	43.50	46.60	44.40	42.60	54.50
22. Nature of Hostel	66.70	56.00	42.10*	48.70	53.40	50.80	48.40	60.60
VI. PERSONAL-EMOTIONAL	49.46	40.52	35.88	43.50	35.52	44.78	37.70	37.60
23. Time to self	61.10	49.30	44.90	53.90	43.70	54.00	47.50	45.50
24. Talk about personal problems	55.60	49.30	46.70	55.70	41.70*	52.40	64.70	51.50
25. Help when sad or depressed	66.70	53.30	55.10	63.50	48.50*	65.10	54.90	45.50
26. Physical health problems	33.30	30.70	18.70	27.00	23.30	27.00	23.80	27.30
27. Planning another child	30.60	20.00	14.00	17.40	20.40	25.40	15.60	18.20
VII PERSONAL-SOCIAL	86.10	72.00	68.70	75.65	69.40	77.00	71.30	69.70
28. Discussion with friends	86.10	72.00	67.30	74.80	68.90	76.20	70.50	69.70
29. Discussion with other parents	86.10	72.00	70.10	76.50	69.90	77.80	72.10	69.70
VIII. SUPPORT-PHYSICAL	62.97	53.33	53.47	58.27	51.30	60.33	52.87	52.50
30. Transportation for child's training	91.70	73.30	67.30*	74.80	71.80	81.00	72.10	63.60
31. Manual support for transportation	69.40	54.70	55.70	60.90	53.90	66.70	53.10	54.50
32. Domestic support for childcare	27.80	32.00	37.40	39.10	28.20	33.30	32.80	39.40

Contd.

Contd.

PARENT NEEDS	PARENT EDUCATION			PARENT SEX		PARENT AGE		
AREAS/NEEDS	PRIMARY (n=36)	SEC-INT (n=75)	DEGREE (n=107)	FEMALE (n=115)	MALE (n=103)	<=35YR (n=63)	36-50YR (n=122)	> 50YR (n=33)
IX. MARRIAGE								
33. Marriage of the child	86.10,	69.30	57.90*	68.70	64.10	60.30	68.90	69.70
X. SEXUALITY								
34. Child Sexuality	91.70	80.00	73.80	81.70	75.70	73.00	80.30	84.80
XI. FINANCIAL	88.87	71.10	52.03***	67.83	61.17	66.67	62.30	69.70
35. Financial help-services	97.20	81.30	57.90***	74.80	69.90	76.20	68.90	78.80
36. Financial help-Training material	97.20	80.00	56.10***	73.90	68.00	73.00	70.50	69.70
37. Financial help-Others	72.20	52.00	42.10**	54.80	45.60	50.80	47.50	60.60
XII. GOVERNMENT-BENEFITS	100.00	94.65	90.65	97.40	89.30*	97.60	91.40	93.90
38. Government Benefits	100.00	97.30	92.50	98.30	92.20	98.40	94.30	93.90
39. Legislation	100.00	92.00	88.80	96.50	86.40**	96.80	88.50	93.90
XIII. VOCATIONAL PLANNING								
40. Vocational Rehabilitation	77.80	88.00	93.50*	91.30	86.40	77.80	94.30	90.90***
XIV. FUTURE PLANNING	92.57	81.77	83.47	85.53	83.20	80.43	84.13	92.93
41. Financial Planning-Future	94.40	85.30	82.20	87.00	83.50	84.10	86.10	84.80
42. Inheritance - Property	88.90	78.70	82.20	82.60	81.60	76.20	81.10	97.00*
43. Financial planning -social security of child	94.40	81.30	86.00	87.00	84.50	81.00	85.20	97.00
XV. FAMILY RELATIONSHIPS	61.15	50.00	47.20	51.70	49.00	50.80	53.25	39.40
44. Family problems	41.70	29.30	22.40	30.40	25.20	28.60	31.10	15.20
45. Impact on other child	80.60	70.70	72.00	73.00	72.80	73.00	75.40	63.60

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

With regard to parents' level of education, results show that least educated parents (primary and below) endorsed greater needs in all areas except in "Vocational training" which was reported significantly more by higher educated parents (Degree +). Results also indicated that generally as the education level of the parents increased the reported parental needs decreased. Least educated parents (primary and below) were found to report significantly greater needs in areas such as "Information", "Hostel", "Financial" and "Marriage". Also, least educated group of parents endorsed significantly greater (15 out of 45) needs (see table 4.2). Results were not found to be significantly different between different levels of parent education especially in need areas, such as

"Personal-Emotional", "Personal-Social", "Sexuality", "Future Planning" and "Family relationships".

Handicapped Child Variables

Analysis of the results based on **handicapped child variables**, in relation to the needs expressed by parents are given in Table 4.3. Parents having mentally retarded children below the age of 6 years reported significantly greater needs such as "Disability condition", "Child rearing", "Child cooperation", "Child development", "Explaining of child's condition" and "Family involvement". Parents having children between 7-12 years of age reported significantly greater needs such as "Child rearing", "Child training by teacher, "Child development", "Explaining child's condition", "Home training" and "Vocational rehabilitation".

Parents having children between 13-18 years of age reported significantly greater needs such as "Disability condition", "Nutrition","Child rearing", "Child training", "Parent-teacher interaction", "Child development", "Explaining child's condition","Family involvement", "Home training", "Financial help", "Training material", "Vocational rehabilitation" and "Financial planning-social security of child". Parents having children above the age of 19 years reported significantly greater needs like "Child sexuality", "Government benefits", "Legislation", "Vocational rehabilitation", "Inheritance property" and "Financial planning-social security of child". This indicates strongly that parents of children between 13-18 years have reported greater range of needs than parents of children belonging to other age groups.

With respect to the sex of the child, parents having daughters endorsed significantly greater needs in "Child cooperation", "Child development" and "Physical health problems". No other needs or areas of needs were found to be significantly different. Having a girl child with mental retardation does produce greater negative impact on the parents (see chapter 2) making them more vulnerable to have more "Physical health problems". On comparing, the first five ranked needs, parents having daughters expressed needs in order of priority: "Expected achievement", "Government benefits", "Training materials", "Adverse Sequelae" and "Reading materials". While parents having sons with mental retardation reported "Legislation", "Expected achievement",

"Government benefits", "Training materials", "Problem behaviours" and information on "Services available". The need for information on "Services available" is reported as a 5th ranked need for parents having sons but 13th ranked for parents having daughters. It has been consistently observed in practice that parents seek out and search for services more when they have sons than when they have daughters with mental retardation. The sample of the present study too indicates the similar bias, that is 161 males Vs 67 female mentally retarded individuals could be included from three centres providing services.

TABLE 4.3
PERCENTAGE ENDORSEMENT OF PARENTS NEEDS : HANDICAPPED CHILD VARIABLES

PARENTS NEEDS	CASE/CHILD SEVERITY			SEX		AGE			
AREAS/NEEDS	MILD (n=60)	MODER-ATE (n=105)	SEV-PROF. (n=53)	MALE (n=151)	FEMALE (n=67)	<=6YR. (n=54)	7-12YR. (N=54)	13-18YR. (n=58)	19+YR. (n=52)
I. INFORMATION-CONDITION	83.07	86.82	91.18	86.43	87.83	87.95	85.18	90.23	83.65
1. Disability condition	81.70	86.70	88.70	84.10	89.60	92.60	81.50	93.10	75.00*
2. Assessment reports	83.30	85.70	94.30	86.80	88.10	87.00	85.20	86.20	90.40
3. Expected achievement	100.00	92.40	96.20	96.00	94.00	90.70	92.60	98.30	100.00
4. Adverse sequelae	90.00	87.60	98.10	91.40	89.60	87.00	90.70	91.40	94.20
5. Reading material	86.70	91.40	90.60	91.40	86.60	92.60	90.70	91.40	84.60
6. Nutrition	56.70	77.10	79.20**	68.90	79.10	77.80	70.40	81.00	57.70*
II. CHILD MANAGEMENT	68.81	75.37	83.81	74.56	78.04	73.80	80.16	81.29	66.47
7. Child rearing	81.70	87.60	94.30	86.80	89.60	90.70	90.70	93.10	75.00*
8. Discipline	85.00	87.60	90.60	88.10	86.60	90.70	85.20	91.40	82.70
9. Problem behaviours	88.30	87.60	98.10	90.10	91.00	88.90	92.60	94.80	84.60
10. Child cooperation	50.00	77.10	88.70***	66.20	86.60***	83.30	75.90	75.90	53.80***
11. Child training	71.70	76.20	83.00	79.50	70.10	59.30	88.90	81.00	76.90***
12. Parent - Teacher interaction	71.70	70.50	81.10	73.50	73.10	55.60	77.80	84.50	75.00***
13. Child development	33.30	41.00	50.90	37.70	49.30*	48.10	50.00	48.30	17.30***
III. FACILITATING INTERACTION	51.65	64.75	52.80	58.95	56.70	64.85	64.80	66.35	35.60**
14. Explanation of child's condition	50.00	63.80	52.80	58.30	55.20	66.70	61.10	67.20	32.70***
15. Family involvement	53.30	65.70	52.80	59.60	58.20	63.00	68.50	65.50	38.50**
IV. SERVICES	79.00	86.10	83.78	83.18	84.46	79.98	86.28	92.06	75.02
16. Services available	81.70	90.50	88.70	86.10	91.00	90.70	81.50	94.80	82.70
17. Decision making school	86.70	83.80	81.10	84.80	82.10	75.90	83.30	93.10	82.10
18. Training materials	90.00	96.20	88.70	92.70	92.50	90.70	94.40	96.60	88.50
19. Home training	78.30	87.60	86.80	85.40	83.60	74.10	96.30	94.80	73.10***
20. Regular / special school effects	79.30	72.40	73.60	66.90	73.10	68.50	75.90	81.00	48.10***

Contd.

Contd.

PARENT NEEDS	CASE/CHILD SEVERITY			SEX		AGE			
AREAS/NEEDS	MILD (n=60)	MODER-ATE (n=105)	SEV. PROF (n=53)	MALE (n=151)	FEMALE (n=67)	<=6YR. (n=54)	7-12YR. (n=54)	13-18YR. (n=58)	19+YR (n=52)
V. HOSTEL	44.15	46.70	54.70	47.00	50.00	39.80	50.00	56.90	44.20
21. Decision making hostel	40.00	42.90	54.70	43.00	49.30	37.00	46.30	58.60	36.50
22. Nature of hostel	48.30	50.50	54.70	51.00	50.70	42.60	53.70	55.20	51.90
VI. PERSONAL-EMOTIONAL	43.34	34.66	45.66	36.94	45.98	38.88	42.98	41.40	35.40
23. Time to self	55.00	43.80	52.80	49.70	47.80	48.00	59.30	46.60	46.20
24. Talk about personal problems	56.70	40.00	58.50*	45.70	56.70	40.70	53.70	51.70	50.00
25. Help when sad or depressed	60.00	48.60	67.90	52.30	65.70	59.30	57.40	62.10	46.20
26. Physical health problems	25.00	21.90	32.10	18.50	40.30***	20.40	24.10	32.80	23.10
27. Planning another child	20.00	19.00	17.00	18.50	19.40	29.60	20.40	13.80	11.50
VII PERSONAL-SOCIAL	79.15	73.80	63.25	71.85	74.60	77.80	65.75	72.45	75.00
28. Discussion with friends	80.00	72.40	62.30	71.50	73.10	77.80	66.70	69.00	75.00
29. Discussion with other parents	78.30	75.20	64.20	72.20	76.10	77.80	64.80	75.90	75.00
VIII. SUPPORT-PHYSICAL	45.80	57.13	61.03	55.53	53.73	52.47	59.03	56.87	51.27
30. Transportation for child's training	68.30	75.20	75.50	75.50	68.70	72.20	79.60	72.40	69.20
31. Manual support for transport.	44.10	61.90	64.20*	56.00	61.20	53.70	66.00	60.30	50.00
32. Domestic support for childcare	25.00	34.30	43.40	35.10	31.30	31.50	31.50	37.90	34.60
IX. MARRIAGE									
33. Marriage of the child	78.30	61.90	62.30	66.20	67.20	55.70	70.40	65.50	76.90
X. SEXUALITY									
34. Child Sexuality	90.00	71.40	81.10*	78.10	80.60	66.70	81.50	77.60	90.40*
XI. FINANCIAL	55.53	64.13	76.07	63.37	67.67	67.27	48.77	73.00	69.23**
35. Financial Help-Services	65.00	72.40	81.10	70.90	76.10	75.90	61.10	75.90	76.90
36. Financial help-Training material	58.30	74.30	79.20*	67.50	79.10	75.90	55.60	79.30	73.10*
37. Financial help-Others				51.70	47.80	50.00	29.60	63.80	57.70***
XII. GOVERNMENT BENEFITS	94.20	91.90	96.20	93.05	94.75	93.50	86.10	94.85	100.00*
38. Government Benefits	96.70	93.30	98.10	96.00	94.00	94.40	88.90	98.30	100.00*
39. Legislation	91.70	90.50	94.30	90.10	95.50	92.60	83.30	91.40	100.00*
XIII. VOCATIONAL PLANNING									
40. Vocational Rehabilitation	96.70	86.70	84.90	90.70	85.10	72.20	90.70	96.60	96.20***
XIV. FUTURE PLANNING	86.10	82.20	86.80	85.67	81.60	74.67	82.07	89.67	91.03*
41. Financial Planning-Future	81.70	87.60	84.90	86.10	83.60	75.90	87.00	86.20	92.30
42. Inheritance - Property	88.30	77.10	84.90	84.10	77.60	72.20	75.90	89.70	90.40*
43. Financial planning -social security of the child	88.30	81.90	90.60	86.80	83.60	75.90	83.30	93.10	90.40*
XV. FAMILY RELATIONSHIPS	45.00	52.40	52.40	51.35	48.50	45.40	58.30	52.60	45.20
44. Family problems	28.30	23.80	35.80	30.50	22.40	24.10	37.00	25.90	25.00
45. Impact on other child	61.70	81.00	69.80*	72.20	74.60	66.70	79.60	79.30	65.40

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

On comparing parents' needs and levels of mental retardation of the child, results indicated parents having severe and profound mentally retarded reported significantly greater needs such as "Nutrition", "Child cooperation", need to "Talk about Personal problems", "Manual support for transportation" and "Training material". Parents of mild mentally retarded however reported significantly greater need and help in managing "Child sexuality problems". No other,parental needs were found to be significantly different between different levels of mental retardation. Results give an indication that parents having severe/profound mentally retarded have a greater need to "Talk about personal problems" in comparison to the parents having moderate or mild mentally retarded. This could possibly be because of 'shattered hopes' in case of parents of severe/profound mentally retarded children and 'hopes still alive' in case of parents of mild mentally retarded individual generating greater worries and tensions.

Family Variables

Results based on **family variables** relating to area of residence, income of parents and nature of family are presented in Table 4.4. It can be seen from Table 4.4 that the parents from non-urban families reported significantly greater needs (14 out of 45 needs) in comparison to the parents from the urban families. These include "Disability condition", "Assessment reports", "Expected achievement", "Nutrition", "Child rearing", "Problem behaviours", "Child co-operation", "Child development", "Explanation of child's condition", "Family involvement", "Marriage of child", "Financial help-services" and in "Financial help-training material". On the other hand, parents from urban families reported two needs "Domestic support for child care" and "Vocational rehabilitation" significantly more than the non urban families. The results do signify that meagre services are available, largely in non urban areas hence the greater needs expressed by parents from non-urban areas. The nature of needs expressed by urban parents reflect the stresses of urban life with lesser natural support systems and lesser chances of the mentally retarded individuals to get naturally integrated in the main stream of urban life.

TABLE 4.4
PERCENTAGE ENDORSEMENT OF PARENTS NEEDS : FAMILY VARIABLES

PARENT NEEDS	AREA OF RESIDENCE		PARENT INCOME		FAMILY PATTERN	
AREAS/NEEDS	NON URBAN (n=73)	URBAN (n=145)	<=1000 (n=100)	>1000 (n=118)	NUCLEAR (n=175)	NON NUCL (n=43)
I. INFORMATION NEEDS	95.7	82.4*	93.00	81.63*	88.30	80.98
1. Disability Condition	100.0	78.6***	92.00	80.50	88.00	76.70
2. Assessment Reports	97.3	82.1***	94.00	81.40	88.60	81.40
3. Expected achievement	100.0	93.1	100.00	91.50	96.00	93.00
4. Adverse sequelae	94.5	89.0	96.00	86.40	92..00	86.00
5. Reading material	87.7	89.0	93.00	87.30	90.90	86.00
6. Nutrition	94.5	60.7***	83.00	62.70***	74.30	62.80
II. CHILD MANAGEMENT	83.2	71.8*	79.00	72.73	77.39	68.41
7. Child rearing	98.6	82.1***	91.00	84.70	89.70	79.10
8. Discipline	93.2	84.8	91.00	84.70	88.00	86.00
9. Problem behaviours	95.9	87.6*	93.00	88.10	91.40	86.00
10. Child Cooperation	80.8	68.3*	73.00	72.00	73.70	67.40
11. Child training	78.1	75.9	78.00	75.40	78.90	67.40
12. Parent - Teacher interaction	78.1	71.0	78.00	69.50	75.40	65.10
13. Child development	57.5	33.1***	49.00	34.70*	44.60	27.90*
III. FACILITATING INTERACTION	68.5	53.1*	63.50	53.80	58.00	59.30
14. Explanation of child's condition	67.1	52.4*	64.00	51.70	57.10	58.10
15. Family involvement	69.9	53.8*	63.00	55.90	58.90	60.50
IV. SERVICES	87.7	81.5	86.00	81.52	86.04	73.46
16. Services available	93.2	84.8	94.00	82.20*	89.10	81.40
17. Decision making school	91.8	80.0*	88.00	80.50	85.10	76.70
18. Training materials	94.5	91.7	91.00	94.10	94.90	83.70**
19. Home training	83.6	85.5	81.00	88.10	89.10	67.40***
20. Regular / special school effects	75.3	65.5	76.00	62.70*	71.40	58.10
V. HOSTEL	54.2	44.9	48.50	47.45	47.70	48.85
21. Decision making hostel	52.1	41.4	47.00	43.20	45.10	44.20
22. Nature of hostel	56.2	48.3	50.00	51.70	50.30	53.50
VI. PERSONAL-EMOTIONAL	38.4	40.4	47.40	33.22*	40.70	35.82
23. Time to self	49.3	49.0	54.00	44.90	48.60	51.20
24. Talk about personal problems	46.6	50.3	60.00	39.80***	50.90	41.90
25. Help when sad or depressed	52.1	58.6	68.00	46.60***	58.30	48.80
26. Physical health problems	21.9	26.9	32.00	19..50*	25.10	25.60
27. Planning another child	21.9	17.2	23.00	15.30	20.60	11.60
VII PERSONAL-SOCIAL	76.0	71.1	78.50	67.75	72.85	72.10
28. Discussion with friends	71.2	72.4	76.00	68.60	71.40	74.40
29. Discussion with other parents	80.8	69.7	81.00	66.90*	74.30	69.80
VIII. SUPPORT-PHYSICAL	54.8	55.1	56.33	53.83	55.53	52.70
30. Trasportation for child's training	79.5	70.3	79.00	68.60	73.10	74.40
31. Manual support for transportation	63.0	54.9	58.00	57.30	58.60	53.50
32. Domestic support for childcare	21.9	40.0**	32.00	35.60	34.90	30.20
IX. MARRIAGE						
33. Marriage of the child	79.5	60.0***	78.00	56.80***	66.90	65.10

Contd.

Contd.

PARENT NEEDS	AREA OF RESIDENCE		PARENT INCOME		FAMILY PATTERN	
AREAS/NEEDS	NON URBAN (n=73)	URBAN (n=145)	<=1000 (n=100)	>1000 (n=118)	NUCLEAR (n=175)	NON NUCL. (n=43)
X. SEXUALITY						
34. Child Sexuality	84.9	75.9	88.00	71.20	81.10	69.80
XI. FINANCIAL	73.1	60.4	72.33	58.17*	65.13	62.80
35. Financial Help-Services	86.3	65.5***	77.00	68.60	72.60	72.10
36. Financial help-Training material	86.6	52.4	79.00	64.40*	71.40	69.80
37. Financial help-Others	46.6	52.4	61.00	41.50***	51.40	46.50
XII. GOVERNMENT BENEFITS	96.6	92.1	98.00	89.85*	93.15	95.35
38. Government Benefits	97.3	94.5	99.00	92.40*	94.90	97.70
39. Legislation	95.9	89.7	97.00	87.30**	91.40	93.00
XIII. VOCATIONAL PLANNING						
40. Vocational Rehabilitation	82.2	92.4*	90.00	88.10	87.40	95.30
XIV. FUTURE PLANNING	80.8	86.2	86.67	82.50	86.10	77.50
41. Finncial Planning-Future	84.9	85.5	90.00	81.40	86.90	79.10
42. Inheritance - Property	76.7	84.8	83.00	81.40	83.40	76.70
43. Financial planning -social security of child	80.8	88.3	87.00	84.70	88.00	76.70
XV. FAMILY RELATIONSHIPS	50.0	50.7	55.00	46.60	52.30	43.05
44. Family problems	23.3	30.3	35.00	22.00*	28.60	25.60
45. Impact on other child	76.7	71.0	75.00	71.20		

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

Parents living in nuclear families expressed three significant needs in comparison to parents living in non-nuclear families. These included need in getting information on "Child development", "Training materials" and help in "Home training" their child. No other need was found to be significantly different.

Parents from lesser income groups (less than Rs.1,000/- a month) expressed significantly 14 out of 45 pool of needs as seen in Table 4.4. The rest of the 31 needs showed statistically no significant differences between parents from lower and higher income groups. In comparing percentages, however, parents from lower income group expressed greater needs in all areas.

IMPLICATIONS FOR SERVICE PROVISION

- Keeping in view the massive endorsement of needs by parents in the present study, there is an urgent need to review the existing predominantly child-centred programmes and to reorient them to meet needs of the parents and families including mentally retarded individuals.

- An objective and systematic assessment of the parental needs from parent's perspectives must preceed any intervention programme.

- Individualised need based intervention programmes must be carried out with parents and goals for intervention should always be set in consultation with the parents.

- In order to seek greater cooperation from parents, it is essential to meet identified parental needs along with the child's specific training needs.

- Understanding and knowledge related to the functioning of the families, group dynamics and also skills in counselling, supportive psycho-therapy are essential for working effectively with families having individuals with disabilities.

- Service providers need to equip themselves with the necessary knowledge and basic counselling skills to communicate diagnosis and needful information to parents in an empathetic and sensitive way.

- Irrespective of the age of the mentally retarded child, parents are concerned about the future planning for their child; they are eager to learn about his/her expected achievement and progress, vocational rehabilitation and issues related to sexuality and even marriage. Professionals need to counsel parents on such issues rather than postpone it for future consultations. It is important that professionals provide parents with honest and needful information before the parents shape their own thoughts and behaviours towards meeting the needs of their child.

- Parents during the initial contact generally convey child related needs to professionals and are guarded to state needs related to personal-emotional aspects. However, a skillful professional through effective counselling skills should be able to tap the personal-emotional needs as well as also the needs related to family relationships, if required. Intervention programmes designed to meet family needs facilitate effective coping.

- Service providers need to have updated information on State and Central Government benefits, legislation and the availability of services to meet this pressing need of many a parent.

- To strengthen the family unit and facilitate healthy interactions and relationships among family members, need based family counselling should be provided.

- Most of the available services revolve around child skill training, at the most involving the mother; the focus of intervention however continues to be the child. Efforts must be made to stretch the services to involve fathers and other family members to build supports for the mother.

- Parent support groups need to be encouraged to help meet various needs of parents such as sharing information and building parent to parent support.

- Indigenous and culture specific models of care which are acceptable to Indian parents need to be developed to meet physical support, needs of parents as also the financial needs.

- Efforts need to be made to set up need based services in non-urban areas. However need for expansion of services in urban areas cannot also be over-looked.

- Efforts should begin early to strengthen the families by meeting their identified needs. This will help retain mentally retarded children with their families providing them with a better quality of life.

- Culturally relevant materials in print, audio or visual must be provided early to the parents and families for building awareness, right knowledge and correction of misconceptions, if present.

- Need based training workshops should be conducted for parents to empower them with the necessary knowledge and skills related to child management needs.

- Programmes for parents need to be conducted which could help clarify issues on sexuality, marriage, and future planning related to financial and social securities of their child.

SOME FURTHER RESEARCH INDICATIONS

Few suggestions for further research are given below:

- In the study, limited number of parent, child and family variables were taken.This could further be extended including variables such as needs of working couples, single parents, provision of domestic help in the family, number of children or whether the birth order of the mentally retarded child influences the needs of the parents. Such information could give further directions to need based interventions.

- It would be useful to understand the nature of needs of parents versus quality and quantity of supports available to parents. Also, whether nature of needs become different when coping styles of parents are different.

- Samples of parents could be drawn using the life cycle approach through critical stages in their child's development and transitions, to elicit needs at different stages of the index child's life.

- Specific needs of older parents caring for their mentally retarded children need to be studied to provide direction to services.

- A detailed study of parents who opted for various reasons to marry their son/daughter having mental retardation, will provide greater understanding of needs of such parents.

- NIMH-Family Needs Schedule (NIMH-FAMNS) (see chapter-3) developed and used for the purpose of assessing needs of parents, siblings and grandparents may be a good starting point. Further detailed checklists could be developed for each of the fifteen areas which are culturally relevant.

- Efficacy of the intervention programmes to meet various needs of the parents and families need to be evaluated.

- Curricula of the existing training programmes in the field of rehabilitation need to be evaluated. Professional courses at both higher and lower levels need to be identified which should include needful inputs in the knowledge and skills to work with families having children with disabilities.

CONCLUSION

This chapter projected various needs of parents which are generated because of having a mentally retarded child in the family. Assessing these parental needs from parents' perspective is crucial in order to provide individualised family intervention programmes. Meeting both parent and child specific needs enhances parent cooperation and involvement. Need based interventions with parents i.e. both mothers and fathers, should start as early as the child is diagnosed having problems of developmental delay or mental retardation. This would help professionals to shape right thinking, attitudes, beliefs and behaviours in the parents rather than spend greater time in undoing the wrong earlier done. But, before all this can happen, it is time for professional audit to review their resources, attitudes and skills to work effectively with the families.

REFERENCES

Bailey D.B. (1987). **Collaborative goal setting with families: Resolving differences in values and priorities for services.** Topics in Early Childhood Education, 7, 59-71.

Bailey D.B., Blasco, P.M., & Simeonsson, R.J. (1992). **Needs expressed by mothers and fathers of young children with handicaps.** American Journal on Mental Retardation, 97, 1-10.

Bailey D.B. & Simeonsson, R.J., (1988). **Assessing the needs of families with handicapped infants.** The Journal of Special Education,22, 1, 117-127.

Beveridge, S.(1982). **Developing partnership:The Anson House Pre-School Project.** In P. Mittler & H. McConaiche (1982) (Evs) Parents and Professionals and Mentally Handicapped People:Approaches to Partnership, 111-123.

Blackard M.K., & Barsh, E.T. (1982). **Parent and professional perceptions of the handicapped child's impact on the family.** Journal of the Association for the Severely Handicapped, 7, 62-70.

Boone H., Sandall, S.A., Loughry, A. & Frederick (1990). **An informal family centered approach to PL.** 99-457: Parental Views. Journal of Early Childhood Education, Spring 1990.

Drew, C.J., Logan, D.R., & Hardman M.L.(1984). **Mental Retardation:A Lifecycle Approach.**

Dunst, C.J. and Leet, H.E. (1987). **Measuring the adequacy of resources in households in young children. Child:Care, Health and Development,** 13, 111-125.

Dunst, C.J., Vance, S.D. and Cooper, C.S. (1986). **A social systems perspective of adolescent pregnancy:** Determinants of parents and parent-child behaviour. Infant Mental Health Journal, 7, 34-38.

Garshelis, J.A. & McConnell, S.R., (1993).**Comparison of family needs assessed by mothers, individual professionals and interdisciplinary teams.** Journal of Early Intervention, 17, 1, 36-49.

Gowen, J.W., Christy, D.S., & Sparling, J., (1993). **Information needs of parents of young children with special needs.** Journal of Early Intervention, 17, 2, 194-210.

Meyer, D.J.(1985). **Fathers of handicapped children.** In R.R.Fewell & P.F. Vadasy (Eds), Families of Handicapped Children, 35-73. ProEd:Austin, TX.

Roberts, M. (1985). **Three mothers lifespan experiences.** In R.R.Fewell & P.F. Vadasy (Eds), Families of Handicapped Children, 193-220. ProEd:Austin, TX. Seed, P. (1980). Children with profound handicap.

Shea, T.M., & Bauer, A.M.(1985). **Parents and teachers of exceptional children.**

Peshawaria, R. & Menon, D.K. (1991). **Needs of families of mentally handicapped children.** Indian Journal of Disability and Rehabilitation, 1, 69-72.

Peshawaria, R., Venkatesan, S., & Menon, D.K.(1988). **Consumer demand of services by parents of mentally handicapped children.** Indian Journal of Disability and Rehabilitation, June-Dec, 112-120.

Whitehead, L., Deiner P.L., & Taccafordi S. (1990). **Parent and professional evaluation.** Journal of Early Childhood Education, Spring.

CHAPTER 5

Facilitators and Inhibitors in Coping

INTRODUCTION

All parents wish for a healthy baby, but some parents though not by their choice are forced into a situation of having a child with mental retardation. Few parents are able to cope up with such a situation much better than the others depending upon their coping skills and resources. Some families are embroiled in a series of acute crisis interspersed with chronic sorrow (Olshansky, 1962), other families accept the reality of disability and love their child for who he/she is (Turnbull & Turnbull, 1990). The ability of the individual to cope with any situation is related to the available supporting internal resources like faith in God, energy, self-determination and external resources like support from the family members, relatives, friends, neighbours, professionals. In this chapter, we examined what are the factors that helped the parents to cope better with the situation of having a child with mental retardation. We also examined the events/things that acted as barriers for effective coping among parents. We analyzed some of the available research findings from the West and from India and in this Chapter present the findings of our investigations with parents which we feel will provide a perspective of parental coping from parents point of view as also generate further research interest in this area.

CONCEPTUAL FRAMEWORK

Facilitators

The presence of a child with mental retardation in the family creates additional needs. Whether the family is able to meet the needs or not is dependent on number of factors like nature of the event, the family resources and its perceptions of the event (Hill, 1949). Unmet needs, tangible or intangible however create stress. Research has indicated that families who are successful in coping with having a child with mental retardation, are able to mobilize their internal and external means of support to deal effectively with the special needs of their child (Kirk & Gallagher, 1989).

Resources that act as facilitators to effective coping can be of two types: internal coping strategies (i.e. coping through passive appraisal, reframing,spiritual and religious support) and external coping strategies (i.e. coping through use of social support or formal support).

Research has indicated the high level of marital satisfaction or support from husband expressed by mothers as an important facilitator in helping the family having a child with mental retardation to adjust better to life (Belsky, 1984; Bristol, 1984; Friedrich, 1979; Friedrich, Wilturner, & Cohen, 1985; Gallagher, 1986). The elements of such support include encouragement, assistance, feedback (Gallagher et al., 1981) and pragmatic help in the completion of tasks important in daily life (Wolfensberger, 1967).In addition, support and help from extended family members like grandparents also act as significant facilitators to coping (Caplan, 1976; Fewell, 1986; Vadasy & Fewell, 1986).

The size of the networks of informal support and density of networks i.e. the extent to which members of the network know and interact with each other is also another important facilitator to effective coping. Research has indicated that larger social networks are associated with more successful coping and adaptation (Hirsch, 1979, 1980; Wilcox, 1981). Families of handicapped children often have smaller informal networks and hence

report more social isolation (Kazak, 1987; Kazak & Wilcox, 1984; McAndrews, 1976, McAlister, Butler, & Lei, 1973). Research also indicates that lower density networks help in effective coping (Hirsch, 1979, 1980; Wilcox, 1981). In addition, other factors reported to act as facilitators in coping include parents having better physical health (Turnbull & Turnbull, 1990); family characteristics like high degree of cohesion and expressiveness; and the presence of active recreation in the family (Bristol, 1984; Mink, Nihira, & Myers, 1983).

Support from professionals also has been reported as a facilitator for coping (Bristol, 1984; Farran, Metzger, & Sparling, 1986; Harris, 1982, 1984). Community agencies/organizations which assist families in keeping their children at home have also been reported as an important facilitator for family coping (Walker, 1989). Research on the internal coping strategies is very limited. According to Turnbull & Turnbull(1990), the most common internal coping strategies used by parents of children with mental retardation include use of passive appraisal, reframing and spiritual support.

Research in India, although very limited has indicated that receiving maximum social-emotional support from spouses, family members, relatives and friends are facilitators to effective coping.

Inhibitors

The ability of the family to cope with any situation will often depend on their strengths and resources. Although the society provides a variety of resources, these are not equally distributed in the population. Consequently, effective coping remains individualized.

Most of the interpretations of the research related to inhibitors to effective coping have been done in context with the research done on variables related to facilitators of effective coping. For example, higher level of marital satisfaction or support from husband expressed by mothers is an important facilitator in effective coping. Interpretations in terms of inhibitors would be less satisfactory marriage and less support from husband.

Research has indicated that factors that act as inhibitors to effective coping vary over the life cycle (Suelzle & Keenan, 1981). Research by Baxter (1986); Butler et al.(1987); Morris (1987); Klien(1977); Suelze & Keenan (1981)has indicated the following as important inhibitors to effective coping: additional financial hardships, stigma, extraordinary demands on time, difficulties in caregiver tasks like feeding, diminished time for sleeping, social isolation, less time for recreational pursuits and difficulties in managing behaviour problems.

Research in India has indicated that inability to perform routine social and household work satisfactorily in the family, interpersonal conflicts either between parents and other children, additional responsibilities, marital disharmony and social isolation were major inhibitors to effective coping (Moudgil, Kumar & Sharma, 1985; Jain & Sathyavathi, 1969, Narayan ,1979).

The present research is an attempt to study:

a) the factors that act as facilitators to effective coping,
b) the factors that act as inhibitors to effective coping.

METHODOLOGY

Sample

The sample included families of 120 children with mental retardation comprising 103 fathers and 115 mothers. The mean age of the sample was 41.5 years (SD = 8.91). 49.1% of the sample had completed education degree and above, 50.9 % of the sample had education below degree. The mean family income of the sample per month was Rs 3242.70 (SD = 2591.5). 98 families were nuclear and 22 were non-nuclear families. 79 families were living in urban areas, 41 families were living in rural and slum areas.

The mean chronological age of individuals with mental retardation was 13.10 years (SD = 7.51). Of the 120 individuals, 84 (70%) were male and 36 (30%) were female. 27.3 % had mild mental retardation (I.Q. = 50-70), 48.3% had moderate mental retardation (I.Q. = 35-49), and 24.4% had

report more social isolation (Kazak, 1987; Kazak & Wilcox, 1984; McAndrews, 1976, McAlister, Butler, & Lei, 1973). Research also indicates that lower density networks help in effective coping (Hirsch, 1979, 1980; Wilcox, 1981). In addition, other factors reported to act as facilitators in coping include parents having better physical health (Turnbull & Turnbull, 1990); family characteristics like high degree of cohesion and expressiveness; and the presence of active recreation in the family (Bristol, 1984; Mink, Nihira, & Myers, 1983).

Support from professionals also has been reported as a facilitator for coping (Bristol, 1984; Farran, Metzger, & Sparling, 1986; Harris, 1982, 1984). Community agencies/organizations which assist families in keeping their children at home have also been reported as an important facilitator for family coping (Walker, 1989). Research on the internal coping strategies is very limited. According to Turnbull & Turnbull(1990), the most common internal coping strategies used by parents of children with mental retardation include use of passive appraisal, reframing and spiritual support.

Research in India, although very limited has indicated that receiving maximum social-emotional support from spouses, family members, relatives and friends are facilitators to effective coping.

Inhibitors

The ability of the family to cope with any situation will often depend on their strengths and resources. Although the society provides a variety of resources, these are not equally distributed in the population. Consequently, effective coping remains individualized.

Most of the interpretations of the research related to inhibitors to effective coping have been done in context with the research done on variables related to facilitators of effective coping. For example, higher level of marital satisfaction or support from husband expressed by mothers is an important facilitator in effective coping. Interpretations in terms of inhibitors would be less satisfactory marriage and less support from husband.

Research has indicated that factors that act as inhibitors to effective coping vary over the life cycle (Suelzle & Keenan, 1981). Research by Baxter (1986); Butler et al.(1987); Morris (1987); Klien(1977); Suelze & Keenan (1981)has indicated the following as important inhibitors to effective coping: additional financial hardships, stigma, extraordinary demands on time, difficulties in caregiver tasks like feeding, diminished time for sleeping, social isolation, less time for recreational pursuits and difficulties in managing behaviour problems.

Research in India has indicated that inability to perform routine social and household work satisfactorily in the family, interpersonal conflicts either between parents and other children, additional responsibilities, marital disharmony and social isolation were major inhibitors to effective coping (Moudgil, Kumar & Sharma, 1985; Jain & Sathyavathi, 1969, Narayan ,1979).

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The mean chronological age of individuals with mental retardation was 13.10 years (SD = 7.51). Of the 120 individuals, 84 (70%) were male and 36 (30%) were female. 27.3 % had mild mental retardation (I.Q. = 50-70), 48.3% had moderate mental retardation (I.Q. = 35-49), and 24.4% had

severe mental retardation (I.Q.=21-34). (For further details on sample selection please refer to chapter 2).

Procedure

All the interviews were conducted by the research staff in the homes of the subjects included in the study. All the 103 fathers and 115 mothers were interviewed individually at their residence in the language of their preference. Data collection was undertaken by the research staff which included the third author and two research assistants who were M.Phil level psychologists. All of them had received training in interview techniques.

Very little is still known about the facilitators/inhibitors to effective coping in Indian cultural setting. The methodology used in the present study was essentially field survey to identify directly from parents the facilitators/inhibitors that helped them or did not help them in coping because of having a child with mental retardation. Interviews were conducted using open ended questions to elicit facilitators/inhibitors to effective coping in families having children with mental retardation. Each of the parents were asked the following questions:

"*What are the things/events that have helped you to cope with the situation because of having a child with mental retardation in the family?*"

"*What are the things/events that didn't help you to cope with the situation because of having a child with mental retardation in the family?*"

Measurement

Information was elicited alongwith the interview related to identifying family needs. Interviews lasted about 15-30 minutes depending upon how elaborate the participant was. All the interviews were tape recorded with prior permission.

All the responses to the open ended questions related to coping were coded and jointly placed in categories for 118 parents by the first, third and fourth authors of this book. The categories were defined in a way that would

facilitate intervention. For the remaining 100 parents, the first, third and fourth authors independently classified the responses into categories and inter-rater reliability established. Inter-rater reliability of 96.8 %, was obtained. It may be noted that when a parent reported number of responses which belonged to a single category, it was scored only once in the given category. For example, in the area of inhibitor, one parent may have reported "loss of support from husband and son" because of having a child with mental retardation. All these responses were rated under loss of support and given a score of 1.

The data was analysed related to three parent variables namely sex, age and education; four variables related to the handicapped child namely, age, sex, severity of mental retardation and presence of behaviour problems; and three variables related to the family namely, family income, nature of family (nuclear/ non-nuclear) and area of residence (urban/ non-urban). Percentages and chi-square tests were used to analyse and compare facilitators and inhibitors with respect to the above mentioned variables.

FINDINGS AND OBSERVATIONS

Facilitators in Coping

Table 5.1 provides definition of categories related to facilitators that helped parents in coping with the situation of having a child with mental retardation in the family.

Parent Variables

The distribution in percentages of the various types of facilitators in coping reported by the parents is presented in Fig 5.1

TABLE 5.1
DESCRIPTION OF CATEGORIES OF FACILITATORS IN COPING

1.	**Faith in God**
2.	**Working problems on own**
3.	**Self determination**
4.	**Inspiration:**
	1. Spouse's positive outlook to life
	2 Spouse's support and understanding

5. **Mutual support between parents**
6. **Physical support**
    1. Spouse
    2. Friends
    3. Siblings
    4. Maternal Grandmother
    5. Paternal Grandmother
    6. Neighbours
    7. Colleagues
    8. Maid servant
7. **Financial support**
    1. Relatives
    2. Church
    3. Elder brother
    4. Maternal Grandparents
    5. Paternal Grandfather
    6. Inheritance
    7. Government benefits
8. **Professional Support**
    1. Psychologist
    2. Homeopathy
    3. Speech Therapist
    4. Trained teacher
    5. Medical Doctor
9. **Professional Management (Areas)**
    1. Behaviour problems
    2. Timely advice on diagnosis
    3. ADL Training
10. **Traditional methods of management**
    1. Oil massage
11. **Acceptance by paternal grandparents**
12. **Institution support**
    1. School
    2. Child Guidance Clinic
13. **Guru's inspiration**
14. **Child characteristics**
    1. No behaviour problems
15. **Easy Accessibility of services**

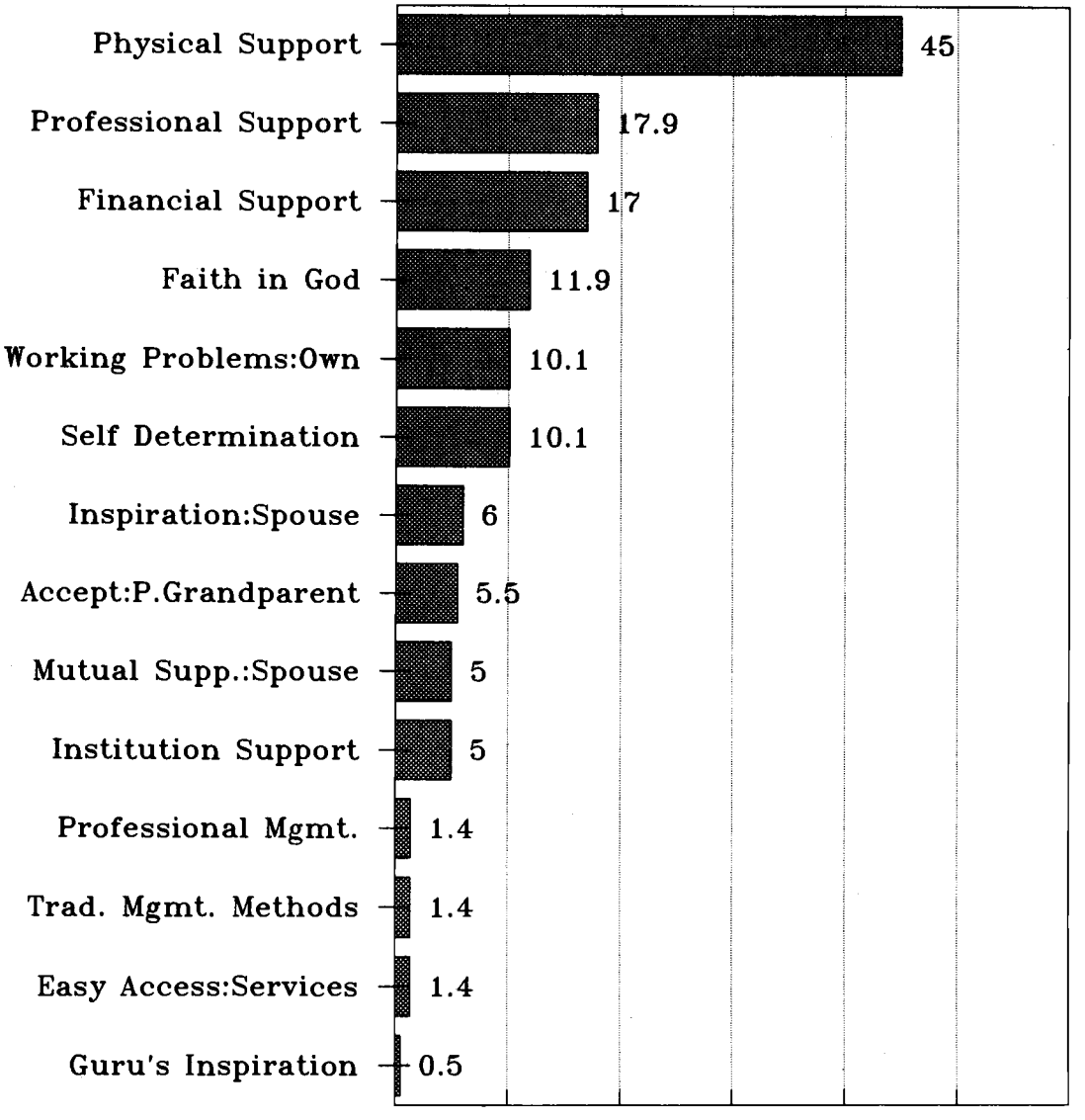

Fig. 5.1
PERCENTAGE DISTRIBUTION OF FACILITATORS
REPORTED BY PARENTS

Results indicate that parents reported "Physical support" from within and outside family as one of the greatest facilitator followed by "Professional support", "Financial support", "Faith in god", "Working problems on own", "Self determination" and others. The significant observation from these was that parents reported external supports provided by others as greater facilitator, than their own internal coping skills such as "Faith in god", "Working problems on own", "Self determination", "Inspiration from spouse or guru". 38 parents (17.4%) reported that nothing had helped them in any way in coping . Whether this is scepticism on part of parents or it is true requires to be further investigated.

The nature of facilitators in coping reported by parents were also analyzed in relation to parent variables such as sex, age and education; child variables such as sex, age, level of mental retardation and presence or absence of behaviour problems and family variables such as type of family, area of residence, and family income.Table 5.2 represents facilitators in coping in terms of parent variables.

Analysis of results based on parent variables with regard to mother/father variable indicated that mothers significantly reported "Physical support: family" as a greater facilitator in comparison to the fathers. Since mothers more than the fathers are under constant pressures to balance between child care needs and household chores "Physical support: family" is reported as a great relief by mothers. Fathers reported "Inspiration spouse" and "Institution support" as significantly higher as facilitators than the mothers. It indicates that some wives due to their attitudes and involvement impress upon their husbands and enthuse confidence in them to face the challenge which fathers have reported. Vice-versa fathers too can contribute in the similar way, though the number of mothers reporting this aspect is small. Looking at the percentages presented in the Table 5.2, it is observed that more mothers seem to be reporting internal coping strategies as greater facilitators than the fathers such as , "Faith in God", "Working problems on own", "Self-determination" and "Inspiration spouse" whereas more fathers reported external supports such as "Institutional support", "Professional support", "Financial support", as beneficial in coping.

TABLE 5.2

FACILITATORS REPORTED BY PARENTS ACROSS PARENT VARIABLES IN PERCENTAGES

Sl. No	Facilitators : Parents	Parent Variables (N=218)							
		Age (in Yrs.)			Sex		Education		
		< =35 (n=63)	36-50 (n=122)	>50 (n=33)	Mother (n=115)	Father (n=103)	< =Primary (n=36)	Sec-Inter (n=75)	Degree + (n=107)
1.	Faith in God	6.3	13.9	15.2	14.8	8.7	5.6	14.7	12.1
2.	Working Problems on:Own	4.8	12.3	21.1	11.3	8.7	0.0	12.0	12.1
3.	Self Determination	1.6	14.8	9.1*	12.2	7.8	8.3	14.7	7.5
4.	Inspiration:Spouse	4.8	6.6	6.1	2.6	9.7*	2.8	2.7	9.3
5.	Mutual Support:Spouse	4.8	5.7	3.0	4.3	5.8	2.8	0.0	9.3*
6.	Physical Support:Family	50.8	45.1	33.3	53.9	35.0**	44.4	40.0	48.6
7.	Financial Support	22.2	15.6	12.1	15.7	18.4	22.2	14.7	16.8
8.	Professional Support	17.5	18.9	15.2	13.9	22.3	22.2	14.7	18.7
9.	Professional Management	3.2	0.8	0.0	0.9	1.9	0.0	2.7	0.9
10.	Traditional Management	1.6	0.8	3.0	0.9	1.9	0.0	1.3	1.9
11.	Acceptance Paternal GP	4.8	4.9	9.1	5.2	5.8	2.8	6.7	5.6
12.	Institutional Support	3.2	4.9	9.1	2.6	7.8*	5.6	5.3	4.7
13.	Guru's Inspiration	0.0	0.0	3.0	0.9	0.0	0.0	1.3	0.0
14.	Child Characteristics	0.0	0.8	4.0	0.9	1.0	2.8	0.0	1.9
15.	Accessibility Services	0.0	0.8	0.0	0.0	1.0*	0.0	0.0	0.9

*** p < 0.05, * p < 0.01, *** p < 0.001**

Analyzing facilitators with regard to age of the parents' no statistically significant results could be obtained. However, on comparing percentages, the results indicate that parents during the middle age i.e., between 36-50 years find "Self determination" as a major facilitator. It is also observed that internal coping supports such as "Faith in God", "Working problems on own", "Self-determination", "Inspiration spouse" are reported by parents more as their age advances whereas facilitators linked with external supports such as "Physical support: family", "Financial support", "Professional management" are seen to decrease with parental age.

With regard to the education levels of parents "Mutual support:spouse" was significantly reported higher as a facilitator in coping by parents who had higher education than by less educated parents. Perhaps sharing at emotional and cognitive levels between the partners i.e., husband and wife increases with education levels. No statistically significant difference could be reached for any of other reported facilitators between the less educated and higher educated parents. The trends generally show that both less educated and higher educated parents reported external supports as greater facilitators than internal coping strategies, however, a few comparisions showed that least educated parents i.e., less than primary level of education reported less internal coping methods and more external coping methods as facilitators in comparison to higher educated parents.

Handicapped child variables

Table 5.3 shows analysis of facilitators in relation to the mentally retarded child variables.With respect to age of the child, only few of the reported facilitators were found to be statistically significant. "Professional management" i.e., help in managing behaviour problems, training in activities of daily living and timely advice on diagnosis was found to be a significant facilitator by parents of children below 6 years of age and child characteristics such as "No behaviour problems", was also reported as a significant facilitator by parents of children above 18 years of age.

TABLE 5.3

FACILITATORS REPORTED BY PARENTS ACROSS HANDICAPPED CHILD VARIABLES IN PERCENTAGES

Sl.No.	Facilitators : Parents	Handicapped Child Variables										
		Age (in Yrs.)				Sex		Severity			Behaviour Problem	
		0-6 (n=54)	7-12 (n=54)	13-18 (n=58)	19+ (n=52)	Male (n=151	Female (n=67)	Mild (n=60)	Moderate (n=105)	Severe (n=53)	Present (n=93)	Absent (n=125)
1.	Faith in God	9.3	13.0	5.2	21.2	11.9	11.9	18.3	11.4	5.7	18.3	7.2*
2.	Working Problems on own	11.1	7.4	5.2	17.3	11.3	7.5	11.7	14.3	0.0*	12.9	8.0
3.	Self Determination	5.6	7.4	10.3	17.3	12.6	4.5	13.3	11.4	3.8	11.8	8.8
4.	Inspiration:Spouse	5.6	5.6	5.2	7.7	5.3	7.5	11.7	3.8	3.8	5.4	6.4
5.	Mutual Support:Spouse	3.7	3.7	5.2	7.7	6.0	3.0	10.0	3.8	1.9	8.6	2.4*
6.	Physical Support:Family	33.3	48.1	53.4	44.2	46.4	41.8	40.0	47.6	45.3	58.1	35.2***
7.	Financial Support	22.2	11.1	15.5	19.2	17.9	14.9	13.3	11.4	32.1**	14.0	19.2
8.	Professional Support	14.8	24.1	19.0	13.5	15.9	22.4	15.0	19.0	18.9	22.6	14.4
9.	Professional Management	5.6	0.0	0.0	0.0*	2.0	0.0	0.0	2.9	0.0	1.1	1.6
10.	Traditional Management	1.9	0.0	3.4	0.0	0.0	4.5*	0.0	1.0	3.8	1.1	1.6
11.	Acceptance Paternal GP	5.6	7.4	3.4	5.8	7.3	1.5	8.3	3.8	5.7	5.4	5.6
12.	Institutional Support	7.4	1.9	3.4	7.7	4.6	6.0	0.0	4.8	11.3*	5.4	4.8
13.	Guru's Inspiration	0.0	0.0	0.0	1.9	0.7	0.0	0.0	0.0	1.9	1.1	0.0
14.	Child Characteristics	0.0	0.0	0.0	5.8*	1.4	1.5	1.7	1.0	1.9	1.1	0.8
15.	Accessibility Services	0.0	0.0	1.7	0.0	0.7	0.0	0.0	1.0	0.0	1.1	0.0

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Other observations based on percentages revealed internal coping strategies as facilitator such as "Faith in God", "Working problems on own", "Self determination", by a greater percentage of parents as their children reach above 18 years of age. This is also in line with the earlier findings wherein parents reported internal coping strategies as greater facilitators when their own age advanced. Parents of children between 13-18 years of age reported "Physical support: family" as a facilitator greater than parents of other age groups of children and "Professional support" by parents of children between 7-12 years of age. Probably parents look out for such a support greater when their children reach this age range. However, these results were not found to be statistically significant.

None of the facilitators reported by parents other than use of "Traditional management methods" were found to be statistically significant in relation to the sex of the mentally retarded child. "Traditional management methods" were found more useful by the parents having a female child, however none of the parents having sons with mental retardation reported this as a facilitator. Observations on comparing results based on percentages indicate internal coping strategies as facilitators such as "Faith in God" was equally reported by parents having sons or daughters with mental retardation but, "Working problems on own" and "Self determination" were reported more by parents having sons than daughters. "Physical support:family", "Financial support" and especially "Acceptance by paternal grandparents" were reported more by parents having sons. Whether such external support is voluntarily made available by others because of gender bias or whether parents tend to seek out such external support more when they have sons than daughters remains a question to be answered.

In relation to the level of mental retardation it can be seen from the table that internal coping strategies become less as facilitators for parents as the severity of mental retardation in their children increases. "Faith in God", "Working problems on own", and "Self determination" are reported higher by parents of mild/moderate mental retardation than of severe/profound

mental retardation. Probably parents having mild/moderate mentally retarded children continue to nurture hope of normalacy in their minds making them more suceptible for seeking support from the Almighty and make greater self efforts. Financial supports are reported significantly more as facilitators for severe/profound children for obvious reasons that financial burden could be greater on such parents to meet multiple needs of such children. Parents of profound/severe children also have reported significantly greater "Institutional support" as a facilitator. Results when interpreted within each level of mental retardation, it continues to indicate that external supports are considered as greater facilitators than internal supports especially the "Physical support:family".

Analysis of results based on presence or absence of behaviour problems reveal that parents having mentally retarded children with behaviour problems find "Mutual emotional support:Spouse" and "Physical support: family/ others" as significantly greater facilitators. Presence of behaviour problems in children are known to produce greater stress to parents. Managing such problems require greater efforts and consistency in handling, hence such supports would be considered as obvious facilitators.

Family variables

Table 5.4 shows analysis of facilitators in relation to the **family variables**. Results indicate that more parents living in non-nuclear families report internal coping methods as facilitators than parents from nuclear families. "Working problems on own" and "Guru's inspiration" are significantly reported as facilitators by more parents from non-nuclear families. Probably living with greater number of people pose greater adjustment challenges necessiating "Working problems on own". Comparatively more percentage of parents from nuclear families report external supports as facilitators such as "Physical support:family/others", "Financial support", "Professional support", "Acceptance from paternal grand parents". Parents from both nuclear and non-nuclear families found "Physical support:family" the biggest facilitator.

TABLE 5.4
FACILITATORS REPORTED BY PARENTS ACROSS FAMILY VARIABLES IN PERCENTAGES

Sl. No	Facilitators : Parents	Family Variables					
		Pattern		Income (In Rs.)		Area of Residence	
		Nuclear (n=175)	Non-nucl. (n=43)	< =1000/- (n=100)	>1000/- (n=118)	Non Urban (n=73)	Urban (n=145)
1.	Faith in God	10.3	18.6	12.0	11.9	6.8	14.5
2.	Working Problems on own	7.4	20.9**	7.0	12.7	4.1	13.1*
3.	Self Determination	9.7	11.6	6.0	13.6	8.8	12.7
4.	Inspiration:spouse	6.3	4.7	3.0	8.5*	2.7	7.6
5.	Mutual Support : Spouse	5.1	4.7	4.0	5.9	1.4	6.9*
6.	Physical Support:family	45.7	41.9	49.0	41.5	32.9	51.0*
7.	Financial Support	17.1	16.3	18.0	16.1	19.2	15.9
8.	Professional Support	18.9	14.0	15.0	20.3	27.4	13.1**
9.	Professional Management	1.7	0.0	1.0	1.7	2.7	0.7
10.	Traditional Management	1.7	0.0	1.0	1.7	0.0	2.1
11.	Acceptance : Paternal GP	6.3	2.3	7.0	4.2	4.1	6.2
12.	Institution Support	4.0	9.3	5.0	5.1	0.0	7.6**
13.	Guru's:Inspiration	0.0	2.3*	1.0	0.0	0.0	0.7
14.	Child Characteristics	1.1	0.0	1.0	1.7	0.0	1.4
15.	Accessibility:services	0.6	0.0	0.0	0.8	0.0	0.7

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Parents from urban areas reported significantly more "Working problems on own", "Mutual emotional support: spouse", "Physical support: family/others", "Institutional support" as facilitators than parents from non-urban areas. However, "Professional support" was reported to have significantly helped parents from non-urban families cope better. The pressures of living in urban areas probably raises the need for greater external support especially from the family hence, "Physical support: family/others" was reported as a facilitator by more number of parents from urban areas. Internal coping methods as facilitators have been also reported more by parents from urban areas than non-urban areas. Analysis within the urban/non-urban variables suggest "Physical support: family" as facilitator for parents of both urban/non-urban area but ranks of other facilitators changes with urban/non-urban variable.

The relationship between facilitators and family income revealed that parents from higher income group with above Rs. 1000/- monthly income reported "Inspiration:spouse", as significantly higher than the parents of lower income group with income of Rs. 1000/- and below. Irrespective of

income, parents reported external supports such as "Physical support:family", "Financial support", "Professional support", as greater facilitators than the internal coping strategies like "Faith in God", "Working problems on own", "Self determination", and "Inspiration from others", that is, spouse or guru. More parents from higher income groups reported internal coping methods as facilitators.

Inhibitors in Coping

Table 5.5 provides definition of categories related to inhibitors

TABLE 5.5
DESCRIPTION OF CATEGORIES OF INHIBITORS IN COPING

1. **Poor physical health of the family members**
   1. Mother
   2. Maternal Uncle
   3. Husband
   4. Index child
2. **Family problems**
   1. Between paternal grandparents and mother
   2. Alcoholic father
   3. Hypersensitive father
   4. Lack of time for the child
   5. Wife has borderline Intelligence
   6. Elder son leaving home after marriage
3. **Loss of support**
   1. Husband's death
   2. Elder son's death
   3. Paternal grandfather's death
4. **Lack of acceptance**
   1. Paternal grandmother
   2. Community
   3. Neighbours
   4. Friends
   5. Father
   6. Relatives
   7. Employers
5. **Over indulgence by others/outsiders**
6. **Financial Constraints**
   1. Marriage of daughter
   2. Debts
   3. No income tax benefits
   4. Unemployed father
   5. Not easy accessibility of government benefits
7. **Transferable Job**

8. **Misguidance by**
   1. Medical doctors
9. **Problems related to professionals**
   1. Wrong advice about child's condition
   2. Lack of information about condition
   3. Negligence on the part of hospital at the time of delivery
   4. Lost hope in doctors
   5. Not enough time dedicated to the child
   6. Unable to maintain regular contact with the professionals due to distance
10. **Lack of information regarding**
   1. Availability of services
   2. Government benefits
   3. Availability of equipment
11. **Lack of facilities**
   1. Medical
   2. Transport
   3. Hospital
12. **Black magic on the child by relatives**
13. **Residential placement/hostel**
14. **Comparison of normal child with index child**
15. **Difficulties in admitting the child to school**
16. **Behaviour problems in child**

The frequency distribution in percentages of the various types of inhibitors is shown in Fig 5.2

Several factors are reported to hinder parental coping because of having a child with mental retardation. The two most inhibiting factors reported by the parents include, "Difficulty in managing Behaviour problems" in their children followed by "Lack of acceptance" of the mentally retarded child by others particularly by paternal grandparents, neighbours, friends, relatives and others in the community. "Financial constraints" was ranked third, "Problems:professionals" as fourth which include wrong advice about child's condition, not providing information about child's condition, negligence, lost hope in doctors, and not enough time dedicated to the child. "Poor physical health of the family members" was ranked fifth as an inhibitor followed by "Misguidance by others", "Loss of support" due to death in the family, "Family problems", "Over indulgence:outsider", "Lack of information", etc.

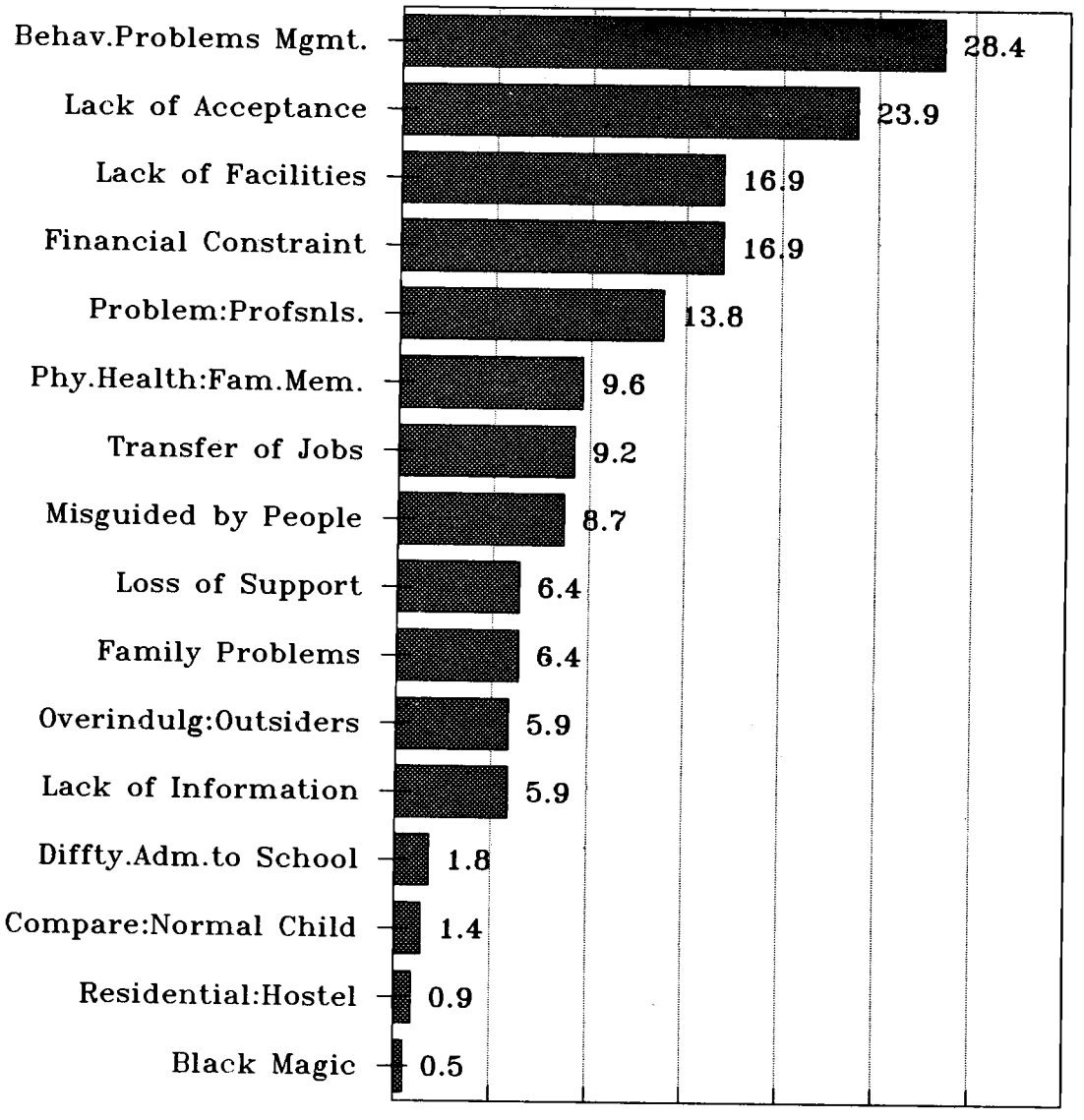

Fig. 5.2
PERCENTAGE DISTRIBUTION OF INHIBITORS
REPORTED BY PARENTS

Presence of behaviour problems in children has been reported by parents to impact them adversely (see Chapter2) and need for management of behaviour problems as also reported in Chapter 4. "Behaviour problems" are reported as the greatest inhibitor by parents in coping as management of behaviour problems is known to put extra demands on the parents and other care givers as also a strain on the support system.

Parent variables

The nature of inhibitors in coping reported by parents were also analyzed in relation to parent variables, as shown in Table 5.6.

TABLE 5.6
INHIBITORS REPORTED BY PARENTS ACROSS PARENT VARIABLES IN PERCENTAGES

Sl. No	Facilitators : Parents	Parent Variables							
		Age in Years			Sex		Education		
		< =35 (n = 63)	36-50 (n = 122)	>50 (n = 33)	Mother (n = 115)	Father (n = 103)	< = Pri. (n = 36)	Sec-Int. (n = 75)	Degree + (n = 107)
1.	Physical Health:Family Members	3.2	11.5	15.2	10.4	8.7	5.6	13.3	8.4
2.	Family Problems	4.8	7.4	6.1	6.1	6.8	5.6	6.7	6.5
3.	Loss of Support	4.8	4.9	15.2	8.7	3.9	2.8	9.3	5.6
4.	Lack of Acceptance	27.0	23.8	18.2	29.6	17.5*	25.0	22.7	24.3
5.	Overindulgence:Outsider	6.3	4.9	9.1	5.2	6.8	0.0	8.0	6.5
6.	Financial Constraints	14.2	14.8	30.3	13.9	20.4	27.8	21.3	10.3*
7.	Transfer of Jobs	4.8	10.7	12.1	7.0	11.7	5.6	8.0	11.2
8.	Misguided by People	6.3	8.2	15.2	7.0	10.7	2.8	10.7	9.3
9.	Problem : Professionals	14.3	13.9	12.1	10.4	17.5	2.8	16.0	15.9
10.	Lack of Information	1.6	9.0	0.0	3.5	8.7	2.8	4.0	8.4
11.	Lack of Facilities	9.5	21.3	15.5	16.5	17.4	5.6	14.6	22.4
12.	Black Magic	0.0	0.8	0.0	0.0	1.0*	2.8	0.0	0.0
13.	Hostel	0.0	0.0	6.1**	0.9	1.0	0.0	0.0	1.9
14.	Compare : child	0.0	2.5	0.0	0.9	1.9	0.0	0.0	2.8
15.	Difficulty Admission : School	0.0	2.5	3.0	1.7	1.9	0.0	0.0	3.7
16.	Behaviour Problems	38.1	26.2	18.2	30.4	26.2	38.9	26.7	26.2

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Significantly more mothers than fathers reported "Lack of acceptance" as an inhibitor in coping. As mothers are generally the direct care takers of their children, they probably are more sensitive to the acceptance/non acceptance of their child by others. Also, it is the mothers due to the greater

burden who require greater help and support from others and when that is not forthcoming non-acceptance is experienced more by the mothers. Some mothers have reported greater non acceptance especially from the paternal grandmother and father of the child. It goes with the observation that it is often the mothers in India who are blamed for producing a child with mental retardation and this blame is generally showered by the paternal grand parents of the child or the father of the child. Both mothers and fathers, however reported "Behaviour problems" as the greatest inhibitor in coping. More fathers than mothers reported "Financial constraints" "Problem:Professionals", "Lack of acceptance", "Transfer of jobs", as inhibitors reflecting strongly their culture specific roles, duties and attitudes. For mothers the first rank inhibitors other than "Behaviour problems" include "Lack of acceptance", "Lack of facility", "Financial constraints" and "Problem: professional" which reflect hindrances in child learning and training, the role which is largely shouldered by mothers.

With regard to the relationships between age of the parents and inhibitors no significant differences were found except for the inhibitor of "Hostel", and as the number of parents reporting this is too small, conclusions are guarded. However, it may be worth while to state that placing mentally retarded individuals in the hostel can create conflicting feelings in Indian parents. Relief could be accompanied with guilt, worry and tension due to seperation. On comparing the first five ranked inhibitors, some dominent trends are observed. The inhibitors perceived by parents below 35 years and between 36-50 years of age are almost same except that "Problem:professional" is reported by parents below 35 years as a greater inhibitor than parents between 36-50 years age. Younger parents seek out information about their child's condition. On the other hand parents between 36-50 years reported "Lack of facility" as a third rank inhibitor probably because parents between 36-50 years get more active to seek out service facilities and get frustrated. More parents above 50 years show somewhat a different profile. For them "Financial constraints" was the first rank inhibitor. "Behaviour problem" management and "Lack of acceptance"

were ranked second, followed by "Lack of facility". "Physical health: family members", "Loss of support" and "Misguided by others" were ranked fourth and "Problem: professionals" moved to the fifth rank in coping.

With regards to coping in relation to parents level of education, "Financial constraints" was found to be a significant inhibitor by least educated parents in comparison to parents having higher education. No other inhibitor was found to be significantly related to parent's education. Parents having secondary to inter level of education also experienced; "Lack of acceptance" as the second inhibitor followed by "Financial constraints", "Problem:professional", "Lack of facility" and "Physical health:family member". Higher educated parents, that is, degree plus also perceived "Behaviour problems" as the biggest inhibitor followed by "Lack of acceptance", "Lack of facility", "Problem:professional", "Transfer:jobs", and "Financial constraint" as the inhibitors in coping in that order. The results also showed that higher educated parents reported more "Problems: professionals" as compared to less educated parents, that is primary and below primary level. The expectations and awareness are high amongst higher educated parents. Similar is the trend seen in the expression of inhibitor "Lack of information" and "Misguided by others", hence, indicating that higher educated parents were more dissatisfied with the professionals than the less educated ones.

Handicapped child variables

Table 5.7 indicates the relationship of the inhibitors with regards to **handicapped child variables**. In relation to age of the mentally retarded child "Lack of facility" was reported as significantly higher as an inhibitor by parents of adult mentally retarded individuals in comparison to parents of younger mentally retarded children. In the present given situation in India, it is true that services for adult mentally retarded individuals are least available which parents probably need the most.

TABLE 5.7

INHIBITORS REPORTED BY PARENTS ACROSS HANDICAPPED CHILD VARIABLES IN PERCENTAGES

Sl.No.	Inhibitors :Parents	Handiccapped Child Variables										
		Age (in Yrs.)				Sex		Severity			Behaviour Problems	
		0-6 (n=54)	7-12 (n=54)	13-18 (n=58)	19+ (n=52)	Male (n=151)	Female (n=63)	Mild (n=60)	Moderate (n=105)	Severe (n=53)	Present (n=93)	Absent (n=125)
1.	Physical Health:Family Member	1.9	13.0	8.6	15.4	9.3	10.4	16.7	2.9	15.1**	3.2	14.4**
2.	Family Problems	9.2	7.4	6.9	1.9	6.0	7.5	13.4	2.9	5.7	4.3	8.0
3.	Loss of Support	5.6	1.9	5.2	13.5	6.6	6.0	8.3	4.8	7.5	9.7	4.0
4.	Lack of Acceptance	22.2	22.2	29.3	21.2	23.8	23.9	28.3	18.1	30.2	12.9	32.0**
5.	Overindulgence:outsider	7.4	7.4	3.4	5.8	6.0	6.0	5.0	6.7	5.7	8.6	94.0
6.	Financial constraints	14.8	13.0	20.7	19.2	16.6	17.9	15.0	14.3	24.5	9.7	22.4*
7.	Transfer of jobs	7.4	7.4	6.9	15.4	9.9	7.5	16.7	6.7	5.7	12.9	6.4
8.	Misguided by people	7.4	3.7	6.9	17.3	11.3	3.0*	11.7	10.5	1.9	14.0	4.8*
9.	Problem : Professionals	9.3	16.7	17.2	11.5	13.2	14.9	13.3	14.3	13.2	24.7	5.6***
10.	Lack of information	0.0	11.1	8.6	3.8	8.6	0.0*	10.0	5.8	1.9	6.5	7.5
11.	Lack of Facilities	12.9	7.4	15.5	21.2*	13.5	12.0	18.3	7.7	34.0	13.9	19.2
12.	Black Magic	0.0	0.0	1.7	0.0	0.7	0.0	0.0	0.0	1.9	0.0	0.8
13.	Hostel	0.0	0.0	0.0	3.8	0.7	1.5	0.0	1.0	1.9	1.1	0.8
14.	Compare : child	0.0	3.7	1.7	0.0	1.3	1.5	1.7	1.0	1.9	1.1	1.6
15.	Difficulty admission:school	1.9	0.0	3.4	1.9	1.3	3.0	5.0	1.0	0.0	1.1	2.4
16.	Behaviour Problems	35.2	37.0	20.7	21.2	25.2	35.8	23.3	30.5	30.2	31.2	26.4

* $p < 0.05$, * $p < 0.01$, *** $p < 0.001$

On comparing percentages, parents of younger age children below 12 years and above 18 years reported "Behaviour problems" as the strongest inhibitors.Whereas parents of children between 13 and 18 years of age found "Lack of acceptance" as the strongest inhibitor.

Parents having male mentally retarded children reported significantly greater inhibitors such as "Misguidance" and "Lack of information". This is an indicator that parents in India do tend to seek out for services and information more for males in comparison to when they have female mentally retarded children hence, frustrations are reported more by them. No other difference in the nature of inhibitors related to the child's sex variable was found to be statistically significant.

Parents having children with mild and severe/profound mental retardation reported significantly greater "Physical health:family members" as an inhibitor in coping. This observation, can be understood far more easily with regard to severe/profound mentally retarded individuals who themselves generally have greater physical health problems. Also, child care demands are greater and prolonged for parents having severe/ profound mentally retarded children necessitating them to be more physically fit to cope up. The same observation for parents of mild mentally retarded is tough to explain except that parents could harbour hopes for their mild mentally retarded individuals to reach near normalacy, incidentally their poor health could have been perceived by them as an inhibitor to achieve it.

The first rank inhibitor for parents of mild mental retardation was reported to be "Lack of acceptance", for parents of moderate mental retardation "Behaviour problems", and parents of severe/profound mental retardation it was "Lack of facility" which is quite justified as presently training facilities are least available to accommodate needs of severe/profound mentally retarded individuals.

On comparing percentages, "Financial constraints" were reported as greater inhibitors by parents of severe/profound mentally retarded children. "Problem:professionals" was almost equally reported as an inhibitor by parents of all levels of mentally retarded children.

In relation to presence /absence of "Behaviour problems", parents having children with behaviour problems reported significantly greater inhibitors related to professionals mishandling such as "Misguidance" and "Problem: professionals". Parents of children with no behaviour problems reported significantly more "Physical health:family member", "Lack of acceptance" and "Financial constraints" as inhibitors. It is understood that helping parents manage behaviour problems require higher technical skills and training and when professionals are unable to match the desired competencies it can cause greater harm than good to the child and the parents.

Family variables

Table 5.8. indicates the relationship between inhibitors and **family variables**. None of the inhibitors reported were found to be significantly different by parents belonging to nuclear or non-nuclear families. However, observations indicate that greater percentage of parents from non-nuclear families reported "Lack of acceptance" as first rank inhibitor and parents from nuclear families reported "Behaviour problems" as the leading inhibitor.

Results based on area of residence indicated that parents residing in urban areas reported significantly greater inhibitors such as "Transfer of jobs", "Misguidance", "Lack of information" and "Difficulties:admission school". Presently services for individuals with mental retardation in India are more centered in urban areas with 200 districts in India still not having any services. When a huge gap exists between the service provision and consumer demand, the concerns of parents are genuine and are reflected in the results. Parents from non-urban areas reported "Behaviour problems" in their children as significantly greater inhibitors which was ranked as

number one inhibitor. Non-urban parents experienced greater "Financial constraints" which was ranked as a third inhibitor by non-urban parents whereas it took first rank with the urban parents.

TABLE 5.8
INHIBITORS REPORTED BY PARENTS ACROSS FAMILY VARIABLES IN PERCENTAGES

Sl. No.	Facilitators : Parents	Family Variables					
		Pattern		Income (In Rs.)		Area of Residence	
		Nuclear (n=175)	Non-nucl. (n=43)	< =1000/- (n=100)	>1000/- (n=118)	Urban (n=145)	NonUrban (n=73)
1.	PhysicalHealth: Family Mem.	9.7	9.3	13.0	6.8	11.7	5.5
2.	Family Problem	6.3	7.0	8.0	5.0	6.9	5.5
3.	Loss of Support	5.1	11.6	5.0	7.6	5.5	8.2
4.	Lack of Acceptance	21.7	32.6	24.0	23.7	25.5	20.5
5.	Overindulgence:Outsider	5.7	7.0	7.0	5.1	6.9	4.1
6.	Financial Constraints	17.2	16.3	24.0	11.0*	13.1	24.7
7.	Transfer of Jobs	8.0	14.0	5.0	12.7*	11.7	4.1*
8.	Misguided People	8.6	9.3	5.0	11.9	11.0	4.1 *
9.	Problem Professional	13.1	16.3	10.0	16.9	16.6	8.2
10.	Lack of Information	6.8	2.3	3.0	8.4*	9.0	0.0 *
11.	Lack of Facility	16.5	18.6	12.0	13.4	21.4	8.2
12.	Black Magic	0.6	0.0	1.0	0.0	0.0	1.4
13.	Hostel	1.1	0.0	0.0	1.7*	0.7	1.4
14.	Compare child	1.7	0.0	1.0	1.7	2.1	0.0
15.	Difficult:Admission to School	1.7	2.3	1.0	2.5	2.8	0.0*
16.	Behaviour Problems	29.7	23.3	27.0	29.7	24.1	37.0 *

*** p < 0.05, ** p < 0.01, *** p < 0.001**

Parents having low income for obvious reasons reported significantly greater "Financial constraints" as inhibitor. Parents from higher income group (greater than Rs 1000/- a month) reported significantly greater inhibitors such as "Transfer jobs", "Lack of information"and "Hostel". These results however, need to be interpreted with caution as number of cases in each category is rather small.

IMPLICATIONS FOR SERVICE PROVIDERS

- While working with parents having children with mental retardation, professionals need to be sensitive to identify concerns of parents which are inhibiting them to cope as also assess the individualized

coping styles of parents in order to facilitate better coping amongst parents.

- Presence of behaviour problems in mentally retarded children has been reported by parents as the greatest inhibitor in coping. Hence, early detection and early behaviour management of behaviour problems is crucial to provide relief to the parents.
- Need based group/individual parent training programs should be launched by every organization providing services for mentally retarded individuals on mass scale. The target should be to include parents of every identified mentally retarded child and to empower them with necessary knowledge and skills in child management. This will help give a more constructive shape to the vast natural resource of parents in our country. Efforts should be made to include both mothers and fathers in such programmes.
- Work with the affected families by the professionals should begin early to foster acceptance and help build needed supports for the family. Programmes which bring together all family members on a common platform and help them to learn to work together for the cause would go a long way in building cohesion in the family.
- To help meet the pressing financial needs of some of the families, strategies need to be evolved to consciously advocate and build financial support from within the family, the Government and from the community.
- Indigenous models which are culture specific need to be evolved to help families which require "Physical support" such as child care or help in household chores especially in times of crisis. Trained volunteers or parent to parent support schemes as also enhancing supports from within the family and neighbourhood could be considered.
- Spread of services and providing need based quality services to the mentally retarded individuals and their families is the challenge with which the professionals will be entering the 21st century. With the

growing awareness among the parents about their strengths and needs, professionals are bound to face greater challenges than ever before. The present study with the families has indicated dissatisfaction with the professional's attitude, knowledge and quality of service provision by a large number of parents. It is time that professionals conduct an error analysis of themselves in understanding the reasons of dissatisfaction among parents and work towards healthy parent professional partnership.

- To facilitate better coping, alongwith building and strengthening external support systems for families, trained counsellors/psychologists need to target training parents in internal coping skills. Parent support groups need to be facilitated as also support groups of 'fathers' need to be initiated which can meet at mutually convenient days and time. As fathers are generally seen less in contact with the professionals due to their work and other compulsions, "Father groups" will give them an opportunity to share their concerns and consider redefining their traditional roles with reference to being in a special situation, that is, father of a child with mental retardation. A supportive and involved father is known to facilitate coping within the family.

- Honest information from the professionals is appreciated by the parents. Professionals need to equip themselves with basic counselling skills to impart even basic information to parents in an empathetic and sensitive way.

- Professionals in their over enthusiasm should not try to shake parents faith in God as it is considered to be a positive internal coping mechanism. However, all efforts should be geared towards helping parents build trust in professionals and training programmes as also encourage parental involvement.

- Individual and family counselling as also marital counselling to facilitate mutual support between parents must be provided early as per the needs of the parents.

SOME FURTHER RESEARCH INDICATIONS

Few suggestions for further research are given below:

- The whole area of coping by Indian parents/families having mentally retarded children remains yet to be understood and researched upon. The findings of the present research are just but a starter.
- It will be useful to identify parents/families who have coped well with the situation of having a mentally retarded child and those who have not coped so well and study the various factors associated with parental coping.
- It will be useful to study the characteristics of parents who are more inclined towards specific methods of coping i.e., internal or external which would help in facilitating coping.
- An in-depth quality of coping by parents at different stages of the life span of their mentally retarded child would provide directions for targeting interventions to promote better coping.
- Cognitive coping styles of parents related to perceptions and attitudes towards mentally retarded children need to be studied. This shall help in restructuring negative cognitions of parents wherever needed to facilitate healthy coping.
- It has been observed during the conduct of present research that parents find supports within the family i.e., from spouse, particularly from father and paternal grand parents as greater facilitators in coping. These factors could be further studied.
- 17.4% of the parents reported in the present study that nothing helped them in coping. Such a sample of parents could be taken up for further study.
- Need based intervention programmes could be conducted to facilitate coping amongst parents and their effectiveness studied.

CONCLUSION

This chapter focused on what helped and what didn't help parents in coping i.e., facilitators and inhibitors in coping with a situation of having a mentally retarded child in the family. This understanding is crucial for facilitating coping amongst parents. To promote greater adjustment among the families professionals need to strengthen both internal coping skills in parents and also build external supports from within and outside the family. Intervention however, should be individualized for parents and families as per their individual needs.

REFERENCES

Baxter, C. (1986). **Intellectual disability. Parental perceptions and stigma as stress.** Unpublished doctoral dissertation, Monash University, Clayton, Victoria, Australia.

Belsky, J. (1984). **The determinants of parenting: A process model.** Child Development, 55, 83-96.

Bristol, M.M. (1984). **The birth of a handicapped child-a holistic model for grieving.** Family Relations, 33, 25-32.

Butler, J.A., Rosenbaum, S., & Palfrey, J.S. (1987). **Ensuring access to health care for children with disabilities.** New England Journal of Medicine, 317, pp 162-165.

Caplan, G. (1976). **The family as a support system.** In G.Caplan & M.Killilea (Eds), Support system and mutual help: Multidisciplinary explorations (pp 19-36). New York:Grune & Stratton.

Farran, D.C., Metzger, J., & Sparling, J.(1986). **Immediate and continuing adaptation in parents of handicapped children: A model and illustration.** In J.J.Gallagher & P.M.Vietz (Eds), Families of handicapped persons (pp 143-166). Baltimore:Brookes.

Fewell, R.R. (1986). **Support from religious organizations and personal beliefs.** In R.R. Fewell & P.F.Vadasy (Eds) Families of handicapped children:Needs and supports across lifespan. Austin, TX. ProEd (pp. 297-316)

Friedrich, W.N. (1979). **Predictors of coping behaviours of mothers of handicapped children.** Journal of Consulting and Clinical Psychology, 47, 1140-1141.

Friedrich, W.N., Wilturner, L.T., & Cohen, D.S. (1985). **Coping resources and parenting mentally retarded children.** American Journal of Mental Deficiency, 90 (2), 130-139.

Gallagher, J.J. (1986). **The family with a child who is handicapped** in J.J.Gallagher & B.Weiner (Eds), Alternative futures in special education. Reston, VA:CEC (pp 13-14).

Gallagher J.J., Cross, A., & Scharfman, W. (1981). **The father's role.** Journal of Division for Early Childhood, 3, 3-14.

Harris, S.L. (1982). **A family system approach to behavioural training with parents of autistic children.** Child and Family Behaviour therapy, 4, 21-35.

Harris, S.L. (1984). **The family of the autistic child: A behavioural -systems view.** Clinical Psychology Review, 4, 227-239.

Hill, R. (1949) **Families under stress.** New York: Harper and Row.

Hirsch, B. (1979). **Psychological dimensions of social networks: A multidimensional analysis.** American Journal of Community Psychology, 7, 263-277.

Hirsch, B. (1980). **Natural support systems and coping with major life change.** American Journal of Community Psychology, 8, 159-172.

Jain, M.C., & Sathyavathi, K., (1969). **A preliminary note on the problems in the families with a mentally retarded child.** Transactions of All India Institute of Mental Health, 9, 23.

Kazak, A. (1987). **Families with disabled children: Stress and social networks in three samples.** Journal of Abnormal Psychology 25, 137-146.

Kazak, A., & Wilcox, B. (1984). **The structure and function of social networks in families with handicapped children.** American Journal of Community Psychology, 12, 645-661.

Kirk S.A., & Gallagher, J.J. (1989). **Educating exceptional children.** (6th Ed). Boston:Houghton Mifflin.

Klein C. (1977). **Coping patterns of parents of deaf-blind children.** American Annals of Deaf, 122, pp. 310-312.

McAlister, R.J., Butler, E.W., & Lei, T. (1973). **Patterns of social interaction among families of behaviourally retarded children.** Journal of Marriage and the Family, 35, 93-100.

McAndrews, I. (1976). **Children with a handicap and their families.** Child:Care, Health and the Development, 2, 213-237.

Mink, I.T., Nihira, K., & Myers, C.E. (1983). **Taxonomy of family life styles.** American Journal of Mental Deficiency, 87(5), 484-497.

Morris, M.M. (1987, July). **Health care:Who pays the bills?** The Exceptional Parent, pp 38-42.

Moudgil, A.C., Kumar, H., & Sharma, S.,(1985). **Buffering effect of social-emotional support on the parents of mentally retarded children.** Indian Journal of Clinical Psychology, 12, 63-70.

Narayan, H.S. (1979). **The impact of mentally retarded children on their families.** M.D. Thesis.

Olshansky, S. (1962). **Chronic sorrow: A response to having a mentally defective child.** Social Casework, 43, 191-194.

Suelzle , M., & Keenan, V. (1981). **Changes in the family support networks over the lifecycle of mentally retarded persons.** American Journal of Mental Deficiency, 86, pp 267-274.

Turnbull, A.P. & Turnbull, H.R. (1990). **Families, professional, exceptionality: A special partnership.** Colombus, OH: Charles E. Merrill.

Vadasy , P.F., & Fewell, R.R. (1986). **Mothers of deaf-blind children.** In R.R. Fewell & P.F.Vadasy (Eds) Families of handicapped children:Needs and supports across lifespan. Austin, TX. ProEd (121-148)

Walker, P. (1989). **Resource review: Family support services.** TASH Newsletter, 15(4), 2-3.

Wilcox, B. (1981). **The role of social support in adjustment to marital disruption: A social network analysis.** In B. Gottlieb (Ed). Social networks and social supoort in community mental health. Beverly Hills:Sage, 99-115.

Wolfensberger, W. (1967). **Counselling the parents of the retarded.** In A.A. Baumeister (Ed), Mental Retardation:Appraisal, education and rehabilitation. Chicago:Aldine (pp 329-400).

CHAPTER 6

Siblings : Impact and Needs

INTRODUCTION

Sibling relationships are the earliest, the longest and the most enduring of all the family relationships (Turnbull & Turnbull, 1990; Cicirelli, 1982) and their influence lasts a life time. Sibling relationship assumes a greater meaning and significance in families having a child with mental retardation. Siblings exert considerable influence over the family member with disability. Siblings are integral members of the family support system. Like any other member of the family, siblings too share the joy and the excitement of a new child in the family and also share the sorrow and disappointment that accompanies the birth of a brother or sister with mental retardation. The roles that siblings play when interacting with each other, such as teacher, playmate or caregiver assumes greater significance if one of the sibling has mental retardation. Sibling relationships provide a context for learning social skills as well as related skills (e.g. language and motor skills). Inspite of this fact, only few researchers have attempted to examine the relationships between the mentally handicapped and non-handicapped sibling. For many years, professionals who worked with the families had maintained a fragmented view of the families by not recognizing or understanding the impact that a child with mental retardation can have on his or her brothers or sisters. Intervention programmes in India have neglected the

contributions that siblings can make to strengthen families having children with mental retardation. Just like parents who have children with mental retardation, siblings having brothers and sisters with mental retardation also need special attention, understanding and support (Powell & Ogle, 1985). In this chapter,we examine how the presence of a member with mental retardation in the family affect the lifestyle of a very significant family support system: siblings. How does having a brother or sister with mental retardation affects them? What are the needs of the non-handicapped siblings? Despite acknowledging the importance of siblings in Indian families, there is a paucity of theoretical and empirical knowledge in understanding or strengthening this resource. We have analyzed the relevant research findings from the West and drawn heavily from our investigation with siblings which we feel will stimulate further research in this much needed area.

CONCEPTUAL FRAMEWORK

Impact: Siblings

Being the sibling of an individual with handicap evokes a range of emotional responses from pride and enjoyment to irritation, jealousy, guilt, grief, fear and resentment and at times just plain confusion (Crnic & Leconte, 1986). Crocker (1981) noted that the presence of a handicapped brother or sister in the family can affect a normal sibling in the following six ways:

a. Normal family patterns like family activities, vacations etc. are altered in a way to accommodate the handicapped child's needs.

b. There may be a greater competition for parental attention and resources as parents may devote more time, energy and resources on the handicapped child rather than on the normal child.

c. Siblings may have misconceptions about the sibling's handicap like they may worry that they are responsible for their brother or sister's handicap or might worry if their own children might be affected.

d. Non-handicapped siblings may have to take over the role of surrogate parent which may act as barrier to their personal social life and may cause them to question their lifelong commitment for their sibling with handicap family member.

e. Parental expectations of non-handicapped siblings may be high in order to compensate for the handicapped child.

f. Over the course of handicapped child's life, parents may experience continuous cycles of grief and conflicts which can influence siblings adjustment process greatly.

Studies have also reported that siblings are adversely affected by the presence of a handicapped child. These effects include greater anxiety, more conflicts with parents and lower sociability (Farber, 1960, 1963; Fowle, 1968; Grossman, 1972). Siblings may experience guilt (San Martino & Newman, 1974), anger (Breslau, Weitzman & Messenger, 1981), have more behaviour problems (Gath,1973) and may have problems in psychological adjustment (Apley, Barbour, & Westmacott, 1967; Tew & Lawerence, 1973). Studies have also indicated that older female siblings are most adversely affected by the presence of a handicapped child because of additional care responsibilities (Cleveland & Miller, 1977; Gath, 1974; Graliker et al., 1962; Grossman, 1972; McHale et al., 1984).

While majority of the studies indicate the presence of emotional or behavioural difficulties among siblings of handicapped children, there are studies that indicate positive outcomes for siblings. These include higher level of tolerance, empathy and altruism (Grossman, 1972), increased sense of maturity and responsibility (Schreiber & Feeley, 1965; Turnbull, Summers, & Brotherson, 1983) and higher than average level of self concept (Mates, 1982). Findings from research suggests that there can be both positive and negative effects on the siblings because of having a brother or sister with mental retardation. Siblings reactions may vary and the intensity and nature of impact on siblings would largely depend upon a number of contributing factors like severity of disability, family resources, family size, religion and culture, parental attitudes, pattern of interaction between the

siblings, and presence of other stressors in the family. (McLoughlin & Senn, 1994; Powell & Ogle, 1985).

Needs : Siblings

The presence of an individual with mental retardation in the family calls for a lot of adjustments on the part of the parents, siblings and other significant family members (Peshawaria & Menon, 1991). Identifying and meeting individual needs of various members in the family is the only way to strengthen the family having a child with mental retardation. Beyond the typical needs experienced by siblings with the birth of a brother or sister, increased stress and additional needs for support are experienced by siblings having brothers or sisters with disability. These unique needs may take the form of family support, assistance, information,etc. Thus, to strengthen families having individuals with mental retardation, interventions must recognize the feelings and needs of the siblings (Turnbull & Turnbull, 1990).

Although siblings may not always explicitly reveal their needs, the research does suggest that siblings of persons with handicaps do have a number of special needs related to themselves, their families, and the community. However, till date very few attempts have been made to empirically study the needs of siblings having brother or sister with mental retardation. Anecdotal reports have been the main source of identifying needs expressed by siblings. Powell & Ogle (1985) contended that special concerns and unique needs of siblings are similar across all handicapping conditions. However, the intensity and chronicity of these unique needs will vary from sibling to sibling based on a number of individual characteristics of the family system. Broad interpretation of the research findings (Powell & Ogle, 1985) indicate that siblings of children with handicaps have a range of needs from knowing the cause of handicap, how to get along with their handicapped sibling better, what to tell their friends about their handicapped sibling, future role, to dealing with parental expectations. Children are a source of strength for parents. This relationship assumes even greater significance when there is a handicapped member in the family and

especially for a country like India where there are no social security systems and siblings naturally assume the role of guardianship of their brother/sister with mental retardation when their parents are no more. Within this context, to strengthen this natural resource of support i.e. the siblings by identifying and meeting their unique needs becomes imperative. The empirical understanding of these siblings having brothers/sisters with mental retardation in Indian families in terms of their impact, needs and involvement are far from adequate and hence need priority.

The present research was conducted to study:

a) the impact on siblings because of having a brother/sister with mental retardation
b) the needs of siblings because of having a brother/sister with mental retardation.

METHOD

Sample

The sample consisted of 66 siblings (35 brothers and 31 sisters) from 56 families having a child with mental retardation. The sample was selected based on the following selection criteria:

a) siblings above 6 years of age were included, and
b) siblings who were staying with the family were included.

None of the siblings included in the sample incidentally had any kind of disability. The mean age of the sample was 19.23 years (SD = 6.47). Majority of siblings (92.4 %) were staying with the family since the birth of the index child. 69.7 % of the sample had secondary education or were continuing college level education. Demographic data of the siblings is presented in Table:6.1.

TABLE 6.1
DEMOGRAPHIC CHARACTERISTICS OF SIBLINGS

Sl.No.	Variable	Frequency Distribution	Total	Mean (S.D.)
1.	Age (Yrs) n (%)	<18 >=18 31 35 (46.9) (53.1)	66 (100)	19.23 (6.47)
2.	Sex n (%)	Sister Brother 31 35 (46.9) (53.1)	66 (100)	
3.	Education n (%)	<=Sec >Sec 20 46 (30.3) (69.7)	66 (100)	

Procedure

All the interviews were conducted by the research staff in the homes of the participants included in the study. The research staff were all trained in the interview method and acceptable interrater reliabilities established. All the 66 siblings were interviewed individually. The interview consisted of two parts. In the first part the interview was conducted using the following open ended question on the impact of having a brother/sister with mental retardation.

"How do you think having a brother/sister with mental retardation in the family has affected you?"

The second part of the interview was conducted using a specifically developed semi-structured interview schedule NIMH-FAMNS (Siblings) to elicit needs of siblings because of having a brother/sister with mental retardation. The NIMH-FAMNS (Siblings) consisted of 15 items (see Chapter 3 for details). Each item helps in identifying 15 different needs mentioned in Fig 6.1 .Each interview took about 30-45 minutes depending upon how elaborate the participant was. All the interviews were tape recorded with permission and coded.

Measurement of impact

All the responses to the open ended questions in the area of impact were coded and jointly placed in categories for 30 siblings by the first and third

authors of this book. The categories were defined in a way that would facilitate intervention. For the remaining 36 siblings, the 1st & 3rd authors independently classified the responses into categories and inter-rater reliability established. Inter-rater reliability of 100 % was obtained between the first and third authors across the domains of impact. It may be noted that when a single sibling reported number of responses which belonged to a single category, it was scored only once in the given category. For example, in the area of "Impact:added responsibilities", one sibling may have reported that she had to feed the child, look after the child when parents go out, etc. All these responses were rated under "Added responsibilities" and given a score of 1.

Measurement of Needs

The needs were analyzed based on the quantitative scoring system of NIMH-FAMNS (Siblings). Each of the need in the NIMH-FAMNS (Siblings) was assigned a numerical score based on the intensity of the need felt. The score of each item on the schedule ranged from 0 to 2 so that higher the score, greater was the intensity of the need expressed by the sibling:

0 (No Need)
1 (Little)
2 (Very Much Need).

For analysing, each need item was scored as 1 or 0 i.e., if need was rated as "little" or "very much a need" it was considered as expressed need and scored as 1. If expressed as "no need" a score of 0 was given. The total score of the all the needs was tabulated. Descriptive statistics (percentages) and chi-square tests were used to analyze and compare the impact and needs with regard to

i. Handicapped child variables:
   a. age
   b. sex
   c. severity of mental retardation
ii. Sibling Variables:
   a. sex

b. age
c. education

*(**Note:** It is to be noted that while interpreting the results, the non-handicapped sibling is referred to as sibling unless otherwise mentioned. Brother/sister referred in the text refers to brother or sister with mental retardation unless otherwise mentioned. If the difference amongst the given variables reached statistical level of significance, it is appropriately mentioned in the text i.e. * $p < 0.05$, ** $p < 0.01$ or *** $p < 0.001$)*

FINDINGS AND OBSERVATIONS

Impact:siblings

Table 6.2 provides definitions of categories related to the impact felt by non-handicapped siblings because of having brother/sister with mental retardation.

TABLE 6.2
DESCRIPTION OF IMPACT CATEGORIES

1. **Restriction : Education :** Unable to continue education as per desire
   'If given a chance, I would have studied more, parents did not allow me to go out for studies'.
   ' I had to give up study as I had to take care of Ramesh'.
2. **Compromise : Recreation** : Unable to carry out recreation activities as per desire
   'We had to think twice before planning a vacation'.
   'Sometimes I had to stay at home and play with my brother than join my friends on a picnic'.
3. **Less Attention:Parents:** Parents paying more attention to child with mental retardation.
   'My mother is always with him'.
   'Even if he starts the fight all the fault is mine'
4. **Teasing : Community** : Being ridiculed by; peers, friends and neighbours in the community.
   'When I go out with Raju, everybody looks at me strangely'.
   'The neighbours make fun of Rohit'.
5. **Added Responsibilities** : Providing physical assistance in carrying out everyday domestic tasks.
   'I assist him to eat properly'.
   'When my parents go out, I take care of him'.
6. **Emotional Reactions** : Reactions like shock, disappointment, denial etc.
   'I feel sad sometimes'
   'I feel quite disappointed'.

7. **Worry : Future**
   'Sometimes I worry on the matter that may be my future husband may not like the role I'm currently playing'.
   'I will also have my family. Will I be able to devote that much time to him?'
8. **Effect : Problem Behaviours** : Effect because of the inability to manage problem behaviours
   'He tears my books'.
   'He insist on only watching his programs on TV. I can't watch mine. If I say anything he fights with me'.
9. **Positive effects** : Experiences inculcated because of having a sibling with mental retardaton.
   'I feel I've more tolerance and patience than friends of my age'.
   'I joined nursing profession'.
10. **Feel isolated**: Feeling of loneliness
   'I feel left out'.
   'I cannot mix with everybody very easily'.
   'Sometimes my friends don't take me in their confidence'.

The frequency distribution in percentages of the various types of impact (in descending order) felt by the non-handicapped siblings of persons with mental retardation are presented in Fig 6.1.

Results indicated that the non-handicapped siblings experienced a wide range of impact. Under negative effects: "Problem behaviours" was reported most commonly by non-handicapped siblings, followed by "Compromise : recreation", "Teasing : community", "Added responsibilities", "Worry future", "Feel isolated", "Restrict education" and "Emotional reactions". Receiving "Less attention from parents" was ranked lowest as regard to the impact felt by the non-handicapped siblings. Positive effects were also noted. The present findings are in line with the Western literature that there can be both positive and negative effects on the non-handicapped sibling (Farber, 1960, 1963; Fowle, 1968; San Martino & Newman, 1974; Breslau, Weitzman & Messenger, 1981; Gath, 1973; Apley, Barbour, & Westmacott, 1967; Tew & Lawerence, 1973; Cleveland & Miller, 1977; Gath, 1974; Graliker et al., 1962; Grossman, 1972; McHale et al., 1984; Schreiber & Feeley, 1965; Turnbull, Summers, & Brotherson, 1983; Mates, 1982 and Cerreto & Miller, 1981).

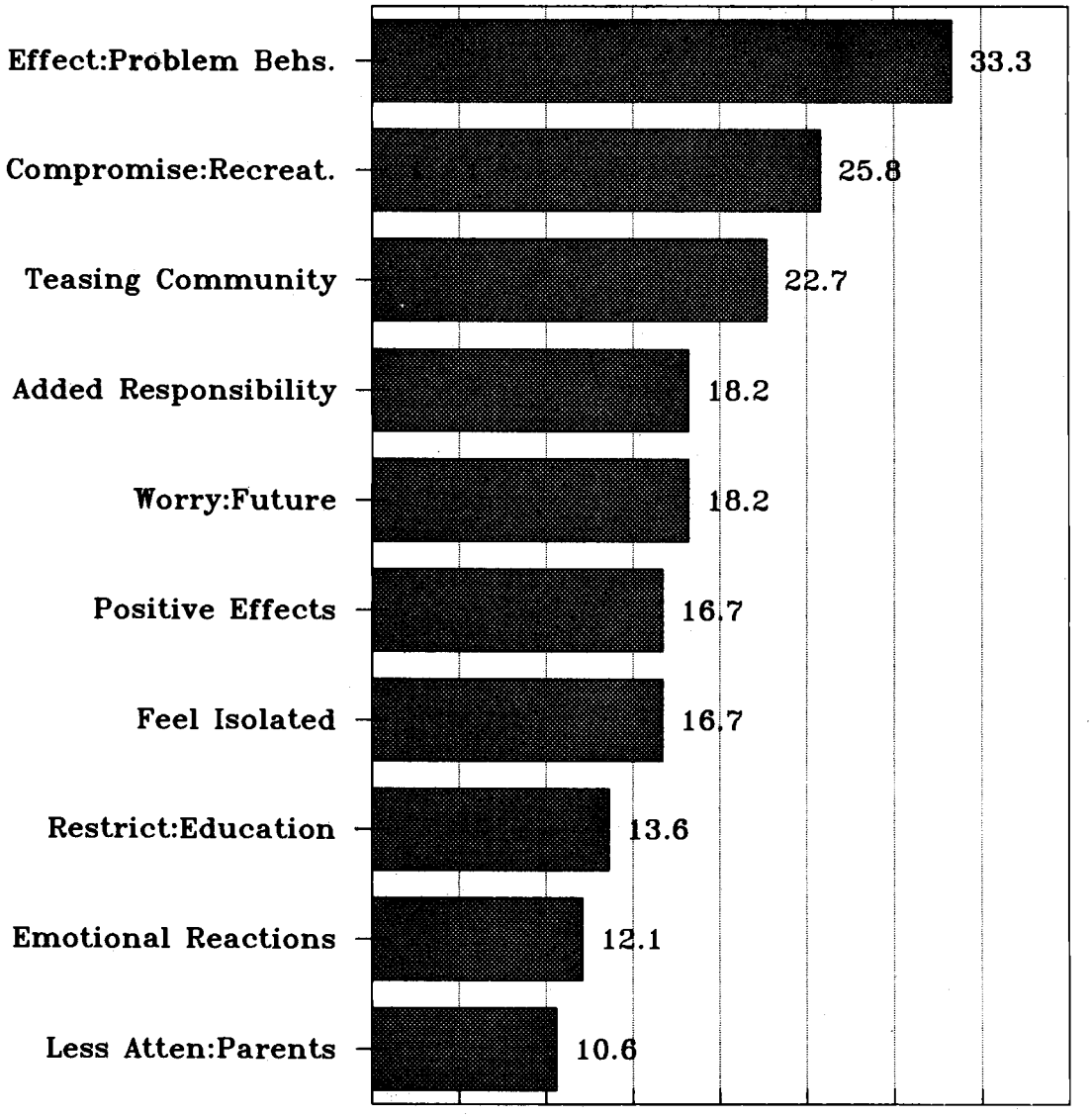

Fig. 6.1
PERCENTAGE DISTRIBUTION OF TYPES
OF IMPACT ON SIBLINGS

The types of impact felt by the non handicapped siblings were analyzed on three variables related to siblings namely, sex, age and education level (Table 6.3) and three variables related to child namely, sex, age and severity of mental retardation (Table 6.4).

TABLE 6.3
PERCENTAGE ENDORSEMENT OF IMPACT ON SIBLINGS : SIBLING VARIABLES

Sl.No.	Impact on Siblings	SIBLING VARIABLES					
		Sex		Age(Yrs)		Education	
		Brother (n=35)	Sister (n=31)	<18 (n=31)	>=18 (n=35)	<SEC (n=20)	>SEC (n=46)
1.	Restrict:Education	17.1	9.7	6.5	20.0	10.0	15.2
2.	Compromise:Recreation	28.6	22.6	22.6	28.6	20.0	28.3
3.	Less Attention: Parents	5.8	16.2	19.4	2.9*	25.0	4.4
4.	Teasing Community	22.9	22.6	19.3	25.7	25.0	21.7
5.	Added Responsibility	14.3	22.6	9.7	25.7*	15.0	19.6
6.	Emotional Reactions	11.4	12.9	9.7	14.3	5.0	15.2
7.	Worry: Future	22.9	12.9	9.7	25.7*	0.0	26.1**
8.	Impact: Problem Behaviours	40.0	25.8	51.6	17.2**	55.0	23.9*
9.	Positive Effects	14.3	19.4	12.9	20.0	5.0	21.7*
10.	Feel Isolated	18.7	11.1	22.6	11.5	30.0	10.8
* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$							

Sibling variables

Though no statistically significant difference was found between the impact reported by the non-handicapped brother or sister, yet on comparing percentages it is observed that non-handicapped sisters felt more neglected by parents, more burdened with additional responsibilities whereas brothers felt greater restriction in pursuing their education and tended to worry more about future of their sibling with mental retardation. Findings do indicate that parents tend to burden female siblings more in index child care, pay less attention to female siblings than male siblings. Male siblings tend to worry about the future more as they prepare to shoulder the responsibility of caring for their sibling with mental retardation especially when their parents are no more there. Siblings both male and female equally tend to feel strongly about

having to make compromises on their recreation time as also face ridicule/teasing by people from the community because of having a sibling with mental retardation.

With respect to age, siblings below 18 years of age significantly reported receiving "Less attention by parents" and experiencing negative effect due to presence of "Behaviour problems" in their brother/sister with mental retardation. "Less attention by parents" could be attributed to number of reasons. Parents under the pressure to cope with the stress of having a child with mental retardation may tend to provide greater attention to their child with disability, spend more time with him/her, overprotect him/her even at the cost of other children's interest leaving non-handicapped children competing for parental attention and feeling neglected. During the initial stages of the mentally retarded individual's life, parents tend to actively seek out information and help in managing the child's condition. In their quest for information and management they overlook the needs of the non-handicapped siblings in the family, resulting in the development of feelings of being ignored by parents. This is further strengthened by the data on impact related to index child's age which indicate that feelings of "Less attention:parents" are more in the non-handicapped sibling when the age of the index child is less than 6 years.

The impact of "Problem behaviours" can be attributed to parents adopting an overprotective attitude with their handicapped child resulting in the younger non-handicapped child bearing the brunt of the index child's action. Also, due to generally non-involvement of the siblings in the training programmes, the siblings wouldn't have learnt how to manage or react when their brother/sister with mental retardation indulges in behaviour problems. Parents too have reported need for help for managing behaviour problems on priority basis (Peshawaria et.al., 1988).

Additionally, siblings above 18 years of age have not reported significantly such an impact as on reaching adulthood they would generally take control and assume responsibility for controlling the behaviours of their handicapped sibling.

Siblings above 18 years of age were significantly affected with "Added responsibilities" and "Worrying about future". Analysis of results based on the variables related to index child indicated that siblings' nature of impact was significantly different and varied within sibling variables rather than in relation to variables related to the child with mental retardation. Hence the findings suggest that siblings do get affected because of having a brother or sister with mental retardation irrrespective of their brother/sister's age, sex or severity of mental retardation. However, siblings tend to worry about the future more when their brother/sister with mental retardation is above 18 years of age. As the age of the non-handicapped sibling advances, the parental and societal expectations regarding the siblings roles also undergoes change. With increasing age, the non-handicapped siblings are expected to play the role of surrogate parents in addition to their usual responsibilities. Also, particularly in Indian settings, it has been commonly observed that parents prefer to keep away their non-handicapped sibling from active involvement in the initial years of the index child's life for various reasons. It is only when the index child and the parents themselves start getting older that they seek active involvement of the non handicapped siblings that too reluctantly for social security reasons which could cause greater "Worry:future" in these older siblings.

Educational status of the siblings significantly influenced the nature of impact. Findings indicate that less educated siblings found managing "Behaviour problems" difficult. Higher educated worried more about the future, may be because education makes siblings more sensitive and aware of the needs for future planning of individuals with mental retardation. This however needs further exploration. Higher educated siblings significantly experienced more positive effects than those who were less educated. It is possible that education helps people to adapt to situations better and turn adversity to their benefit. Also, the sample consisted of more sisters than brothers who were highly educated. Since sisters were found to be taking up greater additional responsibilities related to the index child care, it could be possible that such experiences and interactions with their brothers/sisters might have helped them to develop positive attitudes and effects.

TABLE 6.4
PERCENTAGE ENDORSEMENT OF IMPACT ON SIBLINGS : HANDICAPPED CHILD VARIABLES

Sl. No.	Needs Expressed by Siblings	Handicapped Child Variables (N=66)								
		Sex		Age (Years)				Severity of MR		
		Male (n=48)	Female (n=18)	<=6 (n=7)	7-12 (n=10)	13-18 (n=20)	>18 (n=29)	Mild (n=17)	Mod. (n=33)	Sev-Pro. (n=16)
1.	Restrict: Educaton	14.6	11.1	0.0	20.0	15.0	13.7	23.5	15.2	0.0
2.	Compromise Recreation	29.2	16.7	14.3	30.0	55.0	6.9	35.3	33.3	0.0
3.	Less Attention: Parents	4.2	11.1	14.3	0.0	0.0	20.7	5.9	3.0	31.3
4.	Teasing Community	23.0	22.3	14.3	20.0	15.0	20.7	17.6	15.2	25.0
5.	Added Responsibility	18.8	16.7	14.3	20.0	15.0	20.7	23.5	15.2	18.8
6.	Emotional Reaction	14.6	5.6	28.6	0.0	0.0	20.7	17.6	15.2	0.0
7.	Worry : Future	16.7	22.2	14.3	0.0	5.0	34.5*	17.6	15.2	25.0
8.	Impact : Problem Behaviours	39.6	16.7	28.6	50.0	30.0	31.0	41.2	36.3	18.8
9.	Positive Effects	16.7	16.7	28.6	10.0	15.0	17.2	29.4	12.1	12.5
10.	Feel Isolated	12.5	16.1	28.6	10.0	20.0	13.8	23.5	9.1	25.0
		*p<0.05		** p< 0.01		*** p < 0.001				

Child variables

Siblings nature of impact was found to be significantly different and vary within sibling variables rather than in relation to variables related to the child with mental retardation. Hence, the findings suggest that siblings do get affected because of having a brother or sister with mental retardation irrespective of their brother/sister's age , sex or severity of mental retardation. However, siblings tend to "Worry about the future" significantly more when their brother/sister with mental retardation is above 18 years of age.

Needs: Siblings

The frequency distribution in percentages of the various types of needs (in descending order) expressed by the non-handicapped siblings of persons with mental retardation are presented in Fig 6.2

As presented in Fig 6.2, results indicate that the non-handicapped siblings experienced a wide range of needs. The most common needs the non-handicapped siblings expressed were: "Information about condition of their handicapped brother/sister" and "Information on how to train their brother/sister with mental retardation". Information regarding "Hostel placement" was rated lowest.

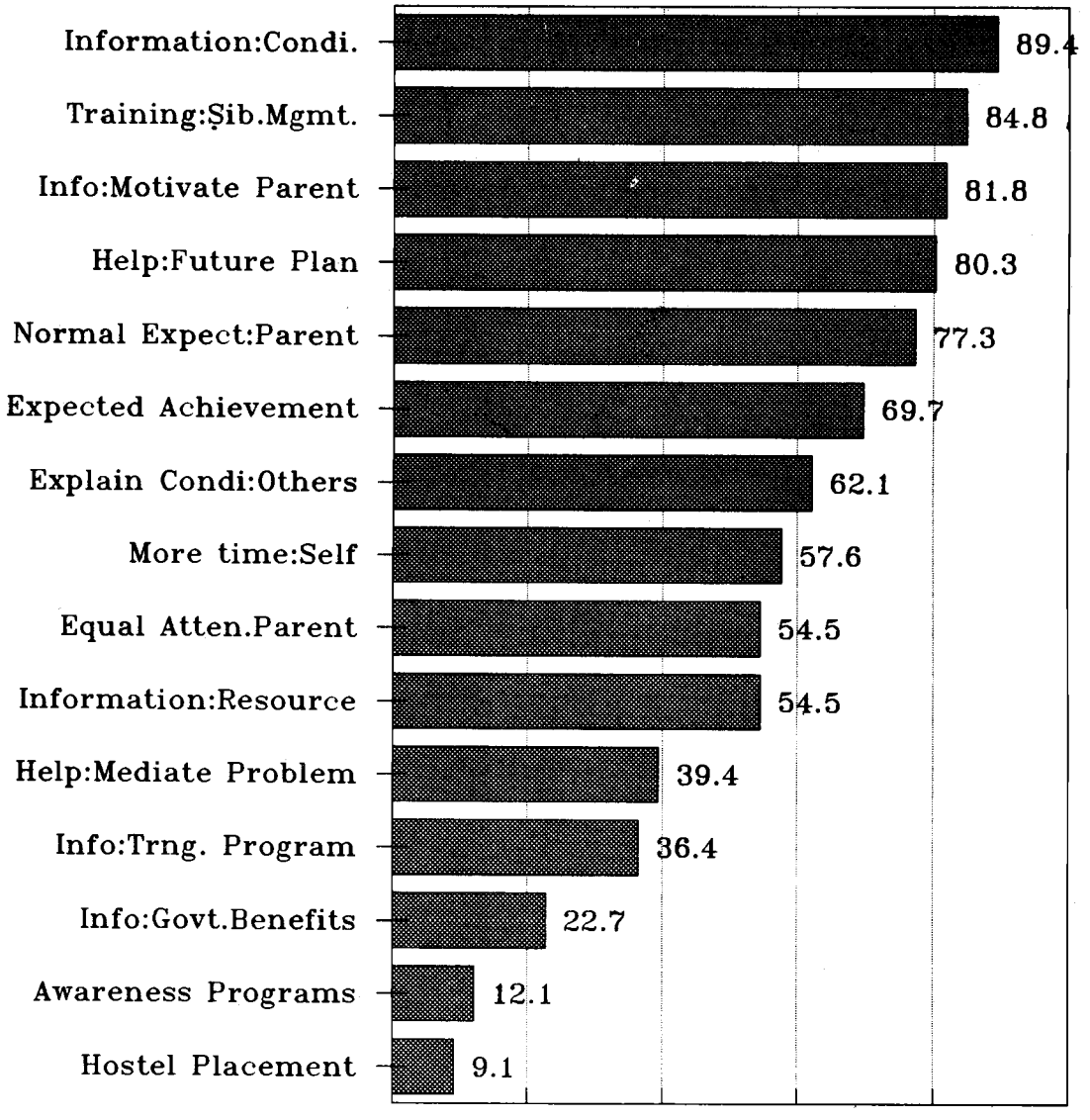

Fig. 6.2
NEEDS OF SIBLINGS
IN PERCENTAGES

The research in the West (Powell & Ogle, 1985) indicate that needs of the non-handicapped siblings are more geared towards knowing the cause of handicap, developing better inter-personal relationships with family members and peers and their role in the future.

The present study does indicate similar needs as reported in the Western literature, yet some of the needs expressed by the siblings were culture specific to the Indian families like "Help:future plan (self)", "Information on how to motivate parents", need to have "Normal expectations" by parents towards non-handicapped siblings, expected "Future achievement" of their brother/sister with mental retardation.

The types of needs expressed by the non-handicapped siblings were analyzed on three variables related to sibling (sex, age and education level, Table 6.5) and on three variables related to index child (sex, age and severity of mental retardation, Table 6.6).

TABLE 6.5
SIBLINGS NEEDS ACROSS SIBLING VARIABLES IN PERCENTAGES

Sl. No.	Needs Expressed by Siblings	Siblings Variables (N=66)					
		Sex		Age (Years)		Education	
		Brother (n=35)	Sister (n=31)	<18 (n=31)	>=18 (n=35)	<=Sec. (n=20)	> Sec. (n=46)
1.	Information:Condition	91.4	87.1	96.8	82.9	100.0	84.8
2.	Expected achievement	65.7	74.2	51.6	85.8**	40.0	82.6**
3.	Training sibling management	82.9	87.1	83.9	85.7	90.0	82.6
4.	Hostel Placement	11.4	6.5	3.2	14.3*	0.0	13.0*
5.	Information explaining condi.	60.0	64.5	77.4	48.6*	80.0	54.3*
6.	More Time: to self	54.3	61.3	71.0	45.7*	85.0	45.7**
7.	Help:Future Plan	77.1	83.9	77.4	82.9	65.0	87.0*
8.	Information : Resources	48.6	61.3	61.3	48.6	55.0	54.3
9.	Information trng. programmes	31.4	41.9	22.6	48.6*	20.0	43.5*
10.	Equal attention	48.6	61.3	83.9	28.6***	85.0	41.3**
11.	Normal expect:parents	71.4	83.9	77.4	77.1	75.0	78.3
12.	Help:mediate family	37.1	41.9	51.6	28.6	65.0	28.3**
13.	Info:Motivate	88.6	74.2	83.9	80.0	75.0	84.8
14.	Awareness program	14.3	9.7	6.4	17.1	10.0	13.0
15.	Information:Govt.Bene	31.4	12.9	25.8	20.0	15.0	26.1

* p<0.05 ** p< 0.01 *** p < 0.001

Sibling variables

Findings from the present study confirm that having a brother or sister with mental retardation does generate number of needs in the non-handicapped siblings. These needs are related to helping their brother/sister with mental retardation, their parents and family, themselves and needs related to cooperation from the community. The needs are related to becoming more aware about the condition/problem of their brother/sister with mental retardation, help in training and management especially of problem behaviours (see Fig 6.1). Siblings have also reported wanting help in making their parents learn to live happily in the given conditions, promote healthy family environment by mediating family conflicts as also give equal attention to all children in the family and have realistic expectations from non-handicapped siblings.

Siblings have also expressed needs for themselves such as to have more time to self or educate themselves through training programmes and help for them for their future planning. They have reported wanting help to seek better cooperation from the community such as need to explain the condition of their brother/sister with mental retardation to others or need to conduct awareness programmes for the people in the community.

Though there is no statistically significant difference found between the needs expressed by the non-handicapped brother or sister, yet on comparing percentages it is observed that non-handicapped sisters have largely expressed greater needs than non-handicapped brothers especially in 10 out of the total 15 needs such as "More time to self", "Training sibling management", "Expected achievement", "Information: explaining condition", "Help in future plan (self)", "Information: resources", "Information:training programs", "Equal attention parents", "Help:mediate family problems" and "Normal expectations". Non-handicapped brothers expressed greater needs related to "Information:condition", "Hostel placement", "Information to motivate parents", "Awareness programs" and "Information on government benefits". Probably the nature of demands and

expectations by parents gives rise to varied impact leading to varied needs among the male and female siblings of individuals with mental retardation.

Siblings above 18 years of age have expressed significantly more needs especially related to "Expected achievement of their mentally retarded sibling", "Hostel placement" and "Information on training programs for non-handicapped siblings". These could be essentially to help prepare and equip them as adults to shoulder greater responsibilities of the sibling with mental retardation. The younger non-handicapped siblings below 18 years of age have expressed significantly more needs in "Seeking information on how to explain the condition of their sibling with mental retardation", "Wanting more time to self" and need for getting "Equal attention from parents". This indicates that younger siblings are not yet mature to find solutions to their own problems and are wanting greater help to defend their rights such as time to self and equal parental attention as also how to conduct themselves with others.

Significant differences have been found between higher educated and lesser educated siblings in expressing some of the needs. Higher educated siblings significantly expressed greater needs in "Expected achievement of their brother/sister with mental retardation", "Hostel placement", "Future planning (self)" and "Information on training programmes for non-handicapped sibling". Possibly higher education, facilitates future planning. Also, parental expectations towards non-handicapped sibling's achievement and contributions toward the child with mental retardation could be higher from more educated siblings leading to such needs. Lesser educated siblings significantly expressed higher needs such as "Information on explaining condition of their sibling with mental retardation"," More time to self", " Equal attention:parents" and "Help:Mediate family problems". In comparison to the higher educated siblings who seemed more concerned in getting the future of their own and their siblings with mental retardation organised, the lesser educated siblings expressed needs and help in their present day to day living and adjustment. The lesser educated siblings possibly got burdened more with additional child care responsibilities and tended to get more ignored by parents.

Child variables

Siblings nature of needs was found to significantly differ and vary within siblings' variables rather than in relation to variables related to child with mental retardation. Although siblings expressed the need for having "Information about the condition" significantly more when their brother/sister had severe-profound mental retardation, the findings in general suggest that siblings do have a number of needs because of having brother/sister with mental retardation irrespective of their brothers/sisters' age, sex or severity of mental retardation.

TABLE 6.6
SIBLINGS NEEDS ACROSS HANDICAPPED CHILD VARIABLES IN PERCENTAGES

Sl. No.	Siblings:Needs	Handicapped Child Variables (N=66)								
		Sex		Age (Years)				Severity of MR		
		Male (n=48)	Female (n=18)	<=6 (n=7)	7-12 (n=10)	13-18 (n=20)	>19 (n=29)	Mild (n=17)	Mod. (n=33)	Sev-Pro (n=16)
1.	Information : condition	89.6	88.4	100.0	90.0	100.0	79.3	64.7	97.0	100.0***
2.	Expected achievement	77.1	50.0	57.1	40.0	70.0	82.8	88.2	63.6	62.4
3.	Training sibling management	87.5	77.8	100.0	80.0	90.0	79.3	70.6	87.9	93.8
4.	Hostel placement	06.2	16.6	0.0	0.0	10.0	13.8	05.9	06.1	18.8
5.	Information explaining condi.	60.4	66.7	85.8	70.0	60.0	55.2	47.1	75.8	50.0
6.	More Time to :self	56.3	61.1	85.7	70.0	65.0	41.4	41.2	69.7	50.0
7.	Help:future plan	83.3	72.2	57.1	80.0	85.0	82.8	82.4	78.8	81.3
8.	Information resources	56.2	50.0	57.1	70.0	50.0	51.7	47.1	54.5	62.5
9.	Information training program	39.6	27.8	42.9	30.0	20.0	48.3	52.9	30.3	31.2
10.	Equal attention	47.7	72.2	85.7	80.0	60.0	34.5*	52.9	60.6	43.8
11.	Normal expect:parents	77.1	77.8	57.1	70.0	95.0	72.4	76.5	75.8	81.3
12.	Help:Med family	39.6	38.9	42.9	50.0	50.0	27.6	29.4	48.5	31.2
13.	Information:Motivate	81.3	83.3	57.1	80.0	90.0	82.8	82.4	78.8	87.5
14.	Awareness program	10.4	16.6	00.0	00.0	10.0	20.7	23.5	6.1	12.5
15.	Information Govt. bene	20.8	27.8	14.3	20.0	20.0	27.6	11.8	24.2	31.2

* p<0.05 ** p< 0.01 *** p < 0.001

IMPLICATIONS FOR SERVICE PROVISION

Findings from the present research provides the following guidelines for services providers

- Siblings do get affected in many ways because of having a brother/sister with mental retardation. The impact does generate a number of special needs in siblings. To help mitigate the negative effects and meet the needs, appropriate intervention programmes for siblings need to be conducted.

- Though patterns of common impact and needs have been statistically found relevant yet intervention programmes for the siblings need to be individualized.

- Siblings do require information on the condition of their brother/sister with mental retardation. They also require knowledge and skills to train and learn to manage behaviour problems of their affected brother/sister effectively. To meet such needs of siblings, need based intervention programmes such as "Behaviour moification workshops" could be conducted.

- Findings also suggest that siblings do not only require help in meeting the needs of their brother/sister with mental retardation but they also require help for themselves in planning for their future.

- Sibling groups could be initiated to help siblings share their concerns with each other. Interactions between siblings could contribute immensely in resolving their emotional reactions and help learn from each others' experiences, the ways of coping with common situations encountered by them. Individual and group counselling programmes for siblings can be of great help.

- Parents and other family members need to become aware of the special needs of siblings. Non-handicapped siblings i.e. brothers and sisters may also need to understand each others' needs and help share the extra responsibilities equally.

- Intervention programmes should emphasize and encourage involvement of non-handicapped siblings with their brother/sister with mental retardation right from the beginning when a child with mental retardation is identified in the family. This would help shape up siblings to accept, adjust and also contribute constructively in strengthening the families.

- Parents are generally the decision makers for their children especially so when the children are still young. Hence, parental acceptance of siblings' involvement becomes one of the crucial factors in facilitating the initiation or conduct of intervention programmes with the siblings. Parents may need to be convinced on the merits of siblings involvement as also that, such an involvement will not adversely affect the non-handicapped sibling.

- Professionals working and interacting with families need to equip themselves with the necessary counselling skills to have better professional relationships with the family members.

SOME FURTHER RESEARCH INDICATIONS

Few indications for further research are presented below:

- The findings on impact and needs of siblings are based on a sample of 66 siblings having a brother/sister with mental retardation and living with the affected family. To draw firm and reliable conclusions, studies need to be conducted on a larger sample.
- Present research is focused on limited number of variables. Effects of other variables such as siblings' birth order, marital status, living with the family/not living with the family etc. could be studied which would give further directions to interventions.
- Present status related to impact, role, support and needs of non-handicapped siblings in the absence of their parents need to be studied. Such information could be very useful in designing suitable intervention programmes to help siblings become effective guardians for their brother/sister with mental retardation.
- Parental expectations of the role and support from their non-handicapped sons and daughters could be studied. This could help professionals to work with parents in developing realistic and healthy expectations from their non-handicapped children and encourage sibling involvement.
- Efficacy of various intervention programmes with the non-handicapped siblings to meet their needs also deserves attention.

CONCLUSION

This chapter dealt with issues related to the impact and needs felt by the non-handicapped siblings because of having a brother/sister with mental retardation. Findings support that siblings who have brothers/sisters with mental retardation experience number of special concerns and hence have special needs. This stresses the fact that we no longer can afford to exclude the siblings when services are provided to the child or the family. In a country like India where there is dearth of formal support services, intervention

efforts should lay emphasis on strengthening the informal sources of support. Siblings are a great natural support to the family. Intervention programmes should place a major emphasis in building such natural support systems which would help the family to function positively.

REFERENCES

Apley, J., Barbour, R.F., & Westmacott,I.(1967). **Impact of congential disease on the family: Preliminary report.** British Medical Journal, 1, 103-127.

Breslau,N., Weitzman, M., & Messenger, K. (1981). **Psychological functioning of siblings of disabled children.** Pediatrics, 10, 85-96.

Cicirelli, V.C. (1982). **Sibling influence throughout the lifespan.** In M.E. Lamb and B.Sutton-Smith (Eds), Sibling relationships: Their nature and significance across lifespan (pp 267-284). Hillsdale, NJ:Erlbaum.

Cleveland, D.W., & Miller, N.B., (1977). **Attitudes and life commitments of older siblings of mentally retarded adults:An exploratory study.** Mental Retardation, 15, 38-41

Crnic K.A., & Leconte, J.M. (1986). **Understanding sibling needs and influences.** In R.R. Fewell & P. Vadasy (Eds). Families of handicapped children (pp 75-98). Austin. ProEd.

Crocker, A.C. (1981). **The involvement of siblings of children with handicaps.** In A. Mulinsky (Ed), Coping with crisis and handicap. New York:Plenum.

Cerreto, M.C., & Miller, N.B. (1981). **Siblings of handicap children.** Unpublished manuscript, University of Texas, Medical Branch, Galveston, Texas.

Farber, B. (1960). **Family organisation and crisis. Maintenance and integration in families with a severely retarded child.** Monographs of the Society for Research in Child Development.

Farber, B. (1963). **Interaction with retarded siblings and life goals of children.** Marriage and Family Living, 25. 1-95.

Friedrich, W.N., & Friedrich, W.L., (1981). **Comparison of psychosocial assets of parents with a handicapped child and their normal controls.**American Journal of Mental Deficiency, 85, 551-553

Gath, A. (1973). The schoolage sibling of mongol children. British Journal of Psychiatry, 123, 161-167.

Gath, A. (1974). **Sibling reactions to mental handicap: A comparison of the brothers and sisters of mongol children.** Journal of Child Psychology and Psychiatry, 15, 187-198.

Graliker, B.V., Fishler, K., & Koch, R. (1962). **Teenage reactions to a mentally retarded sibling.** American Journal of Mental Deficiency, 66, 888-894.

Grossman, F.K. (1972). **Brothers and sisters of retarded children: An exploratory study.** Syracuse, NY. Syracuse University Press.

Mates, T.E. (1982). **Which siblings of autistic children are at greater risk for development of school and/or personality difficulties?** Paper presented at the annual meeting of the National Society for Autistic Children, Omaha, NB.

McHale, S.M., Simeonsson, R.J. & Sloan, J. (1984). **Children with handicapped brothers and sisters.** In E. Schopler & G.Mesibov (Eds), The effects of autism on the family (pp 327-342). New York: Plenum.

McLoughlin, J.A., & Senn, C. (1994). **Siblings of children with disabilities.** In S.K.Alper, P.J.Schloss and C.N.Schloss (Eds), Families of Students with disabilities. Boston, Allyn and Bacon.

Peshawaria, R., Venkatesan, S., & Menon, D.K. (1988). **Counsumer demand of services by parents of mentally handicapped children.** Indian Journal of Disability & Rehabilitation, June-Dec, 112-120.

Peshawaria, R. and Menon, D.K. (1991). **Needs of families of mentally handicapped children.** Indian Journal of Disability and Rehabilitation, 1, 69-72.

Powell, T.H, & Ogle, P.A. (1985). **Brothers and sisters-A special part of exceptional families.** Baltimore: Paul H.Brookes.

San Martino, M., & Newman, M.B.(1974). **Siblings of retarded children: A population at risk.** Child Psychiatry and Human Development, 4, 168-177.

Schreiber, M., & Feeley, M. (1965). **Siblings of retarded: A guided group experience.** Children, 12 (6), 221-225.

Tew, B. & Lawerence, K.M. (1973). **Mothers, brothers and sisters of patients with spina bifida.** Developmental Medicine and Child Neurology, 15, 69-76.

Turnbull, A.P., Summers, J.A., & Brotherson, M.J. (1983). **Working with families with disabled members:** A family systems approach. Unpublished manuscript.

Turnbull, A.P., & Turnbull, H.R. (1990). **Families, professional, and exceptionality:** A special partnership. Columbus: Merrill.

We have learned not to stunt a child's growing body with hard labour; we must now learn not to break his growing spirit by making him a victim of our anxieties.

Erik Erickson

CHAPTER 7

Grandparents: Support, Impact and Needs

INTRODUCTION

Grandparents are one of the significant natural support providers to a family having a child with mental retardation. Grandparents constitute important part of the environment that the index child must inevitably interact. Typically in India, being elders in the family, grandparents to a large extent influence the decision making related to child care, nursing, nutrition and wide ranging matters in family life. Depending upon their resources, the availability of time, their age and physical health, most often the grandparents are drawn into the role of caregivers or supervisors of caregivers.

With rapid urbanization, even though the traditional joint family system is fast disintegrating, yet grandparents continue to play an important and significant role which has direct bearing on the child with mental retardation and the family.

Until recently, majority of the professionals and researchers while working with families of individuals with mental retardation have focussed exclusively on the parents, that too, on the mothers and the individuals with disability. Despite acknowledging the importance of family network members, by and

large, researchers have either neglected or delegated to secondary importance the effect the handicapped individual has on his or her significant family members. In this chapter, we examined how the presence of a member with mental retardation affected the lifestyle of very significant family members: grandparents. How did birth of a child with developmental disability affect them? How were they supporting the child's immediate family? What were their needs? While acknowledging the importance of extended family supports in Indian families, there is a paucity of theoretical and empirical knowledge to verify this. We analyzed the relevant research findings from the Western literature and drew heavily from our investigation with grandparents which we felt will open doors for further research in this much needed area.

CONCEPTUAL FRAMEWORK

The arrival of a new born baby is a time for rejoicing and excitement in a family. Grandparents look forward to the birth of their grandchild. The birth of a grandchild with disability however can have a variety of adverse reactions on the grandparents. Grandparents tend to react emotionally to both the grandchild and other members of the family when crisis related to disability grips the family. Research in the West has revealed that the birth of a grandchild with disability evokes different emotions than those produced by the birth of a healthy grandchild (Meyer & Vadasy, 1986). According to Meyer and Vadasy (1986), grandparents often deny the grandchild's problem, trivialise it or fantasize about unrealistic cures. Grandparents may feel angry, depressed or even experience resentment (Turnbull & Turnbull, 1990) and in some cases may turn this anger on their daughter-in-law or son-in-law (Ehly, Conoley & Rosenthal, 1985). Another reported concern has been the paternal grandmother's resentment of her daughter-in-law for not producing a normal child (Pieper, 1976). Strong adverse reactions such as these can prove a hindrance to parents and the family as they cope up with the crisis of having a handicapped child. This leads to a decrease in family contact and burdening the special family with greater sense of social isolation (Mallory, 1981). (Hornby & Ashworth (1994)) in their survey of parents of children with severe disabilities found that there was a low level of support from grandparents. The nature of

the social and emotional support that grandparents provide to their own children influences the ability of the parents to cope with the crisis. Consequently, the family has to learn not only to cope with their own emotions but also to deal with the grandparents reactions (Seligman & Darling, 1989).

The importance of grandparents in Indian families was succinctly expressed by a mother in our study:

> *"If the paternal grandparents accept the child with mental retardation as he is, 80 % of our problems are solved."*

Many grandparents look forward to their participation in their child's life. The literature in the West mostly related to grandparents of non-disabled children describes various types of supports grandparents provide to the family which seem to corroborate with the anecdotal reports in the Indian families. Baby sitting is one of the most frequently cited ways grandparents help their adult children (Robertson, 1977; Shanas, 1967; Sussman, 1953; Townsend, 1957). In addition, grandparents provide direct financial help to their children (Sussman, 1953), or indirect aid by buying gifts for their grandchildren (Robertson, 1977; Boyd, 1969) and help defray the grandchildren's educational expenses (Bell, 1968). Grandparents have been found to serve as mediators in the conflicts between parents and their children (Schorr, 1960), as well as acting as a friend to their grandchildren (Radcliffe-Brown, 1952).

Although the review indicates that the major role of the grandparents has been to provide support to the family, very few western studies and practically none in Indian settings has systematically examined the role grandparents play when there is a member with mental retardation in the family. Sonnek (1983) conducted a qualitative study of maternal grandparents role in families with a handicapped child between birth and three years of age and found that maternal grandparents were source of assistance, caregiver, giftgiver, playmate and teacher therapist. Although there didn't appear to be separate activities for grandmothering non-handicapped children versus grandmothering handicapped children, there tended to be more reference to the activity "Teacher/Therapist" in regard to grandmothering a handicapped child.

The role grandparents play in Indian families was stated very effectively by a parent in our study:

> *"I was able to cope up with the crisis better because of having supportive in-laws. They went along with me always without any misgivings. Now, since they are no longer alive, I realize the contribution they had made."*

The present research was an attempt to study

a) grandparenting activities or the role and support grandparents were providing to the family having a child with mental retardation;

b) the impact on grandparents because of having a grandchild with mental retardation;

c) the needs of grandparents because of having a grandchild with mental retardation.

METHOD

Sample

120 families having children with mental retardation were studied out of which only 18 families were identified having grandparents living with them. The sample thus included 22 grandparents from these 18 families. The sample consisted of 6 grandfathers and 16 grandmothers. The mean age of the sample was 64.0 years (SD = 5.12). 4 families had both grandparents living with them. 14 paternal grandmothers, 2 maternal grandmothers and 6 paternal grandfathers participated in the study. Description of the socio-demographic variables of the sample is presented in Table:7.1.

Procedure

All the interviews were conducted by the research staff in the homes of the participants included in the study. All the 22 grandparents were interviewed individually.

TABLE 7.1
DEMOGRAPHIC CHARACTERISTICS OF GRANDPARENTS

Sl. No.	Variable		Characteristics		Total (%)	Mean (SD)
1.	AGE (Yrs.)	n (%)	< 65 13 (59.1)	> = 65 9 (40.9)	22 (100)	64.0 (5.12)
2.	SEX	n (%)	G.MOTHER 16 (72.7)	G.FATHER 6 (27.3)	22 (100)	
3.	EDUCATION	n (%)	upto 10th 15 (68.2)	above 10th 7 (31.8)	22 (100)	

The interview was semi-structured focussing on three primary areas of interest i.e. to study the i) role/support, ii) impact and iii) needs of grandparents. The following open-ended questions were used to elicit information related to these three areas:

"*How are you as a grandparent helping the family?*"

"*How do you think having a grandchild with mental retardation in the family has affected you?*"

"*What are your needs because of having a grandchild with mental retardation?*"

Each interview took about 30-45 minutes depending upon how elaborate the respondent was. All the interviews were tape recorded with permission and coded.

Measurement

All the responses to the open ended questions in the areas of support provided, impact and the needs were coded and jointly placed in categories for 12 grandparents by the first and third authors of this book. The categories were defined in a way that would facilitate intervention. For the remaining 10 grandparents, the first and third authors independently classified the responses into categories and inter-rater reliability established. Inter-rater reliability of 94.7 %, 95.5 % and 96.3 % was obtained between the first and third authors across the domains of support, impact and needs of grandparents respectively. It may be noted that when a single grandparent reported number of responses

which belonged to a single category, it was scored only once in the given category. For example, in the area of impact, extra care:physical, one grandparent may have reported that he/she had to give bath to the child, feed the child, look after the child when parents go out etc. All these responses were rated under extra care:physical and given a score of 1. Similarly in the area of support, one grandparent may have reported providing financial support for a number of reasons such as for medicines, towards house rent, buying toys, etc. These were all rated under financial support and given a score of 1. The same was followed for needs too. Due to the small sample size, only descriptive analysis (comparison of percentages) of the responses across grandparent variables (age, sex and education level) and grandchild variables (age, sex and level of mental retardation) was conducted.

FINDINGS AND OBSERVATIONS

Grandparents : Support

Table 7.2 provides definitions of categories related to the support provided by the grandparents of children with mental retardation.

TABLE 7.2
DESCRIPTION OF GRANDPARENTS SUPPORT CATEGORIES

1.	**Child Care:** Providing physical assistance to the family in caring for the child with mental retardation. Not amounting to correction or instruction. 'I give bath to my grandchild.' 'I look after him when his parents go to work.'
2.	**Financial Support:** Providing cash assistance to the family which directly or indirectly affects the index grandchild. 'I buy the medicines for him.' 'My pension helps the family.'
3.	**Household Chores:** Providing physical assistance to the family in carrying out everyday domestic tasks. 'I cook for the family.' 'I clean the house.'
4.	**Emotional Support:** Providing assistance to the the family in dealing with emotions/feelings. Not amounting to professional guidance. 'I'm there for my daughter when she is upset.' 'My daughter talks to me when she feels stressed.'

5. **Sibling Care:** Providing assistance to the non-handicapped sibling in his/her day to day activities.
   'I help Ramesh's sister Suneeta to complete her home work.'

6. **Decision Making:** Provide guidance and direction to the family on various issues related to family life.
   'My decision to the family related to finances is always accepted.'
   'I make decisions for the family in matters related to schooling and marriage.'

7. **Training:Grandchild:** Providing physical assistance to the family in caring for the child with mental retardation. Carrying out training program.
   'I do the exercises prescribed by the doctor daily.'
   'I only take my grandchild to school.'

8. **Recreation:Family:** Providing opportunities for recreation activities for family members.
   'I take my grandchildren to the fair.'
   'I take my (index) grandchild with me for morning walks everyday.'

9. **Mediate Family Conflicts:** Acting as mediator in dealing with conflicts between parents that can arise because of having a child with mental retardation.
   'I have to step in when my son and daughter-in-law argue with each other.'
   'When my son and daughter-in-law quarrel with each other I've to calm them down.'

The frequency distribution in percentages of the various types of support (in descending order) provided by grandparents in a family having a child with mental retardation are presented in Fig 7.1.

Data indicate that grandparents living with the family having a child with mental retardation reported providing a wide nature of support to the family ranging from "Child care" support to providing "Emotional support" to the family. The most common assistance that grandparents extended to the family involved "Child care" support activities, doing "Household chores", providing "Financial support", "Decision making" in matters such as education, financial and marriage issues. Other areas of support included "Recreation:family", "Mediate family conflicts", assisting the family in caring for the non-handicapped sibling, i.e., "Sibling care" and "Training grandchild" with handicap. However, "Emotional support" provided by grandparents to their children i.e. parents of the child with mental retardation is reportedly ranked quite low.

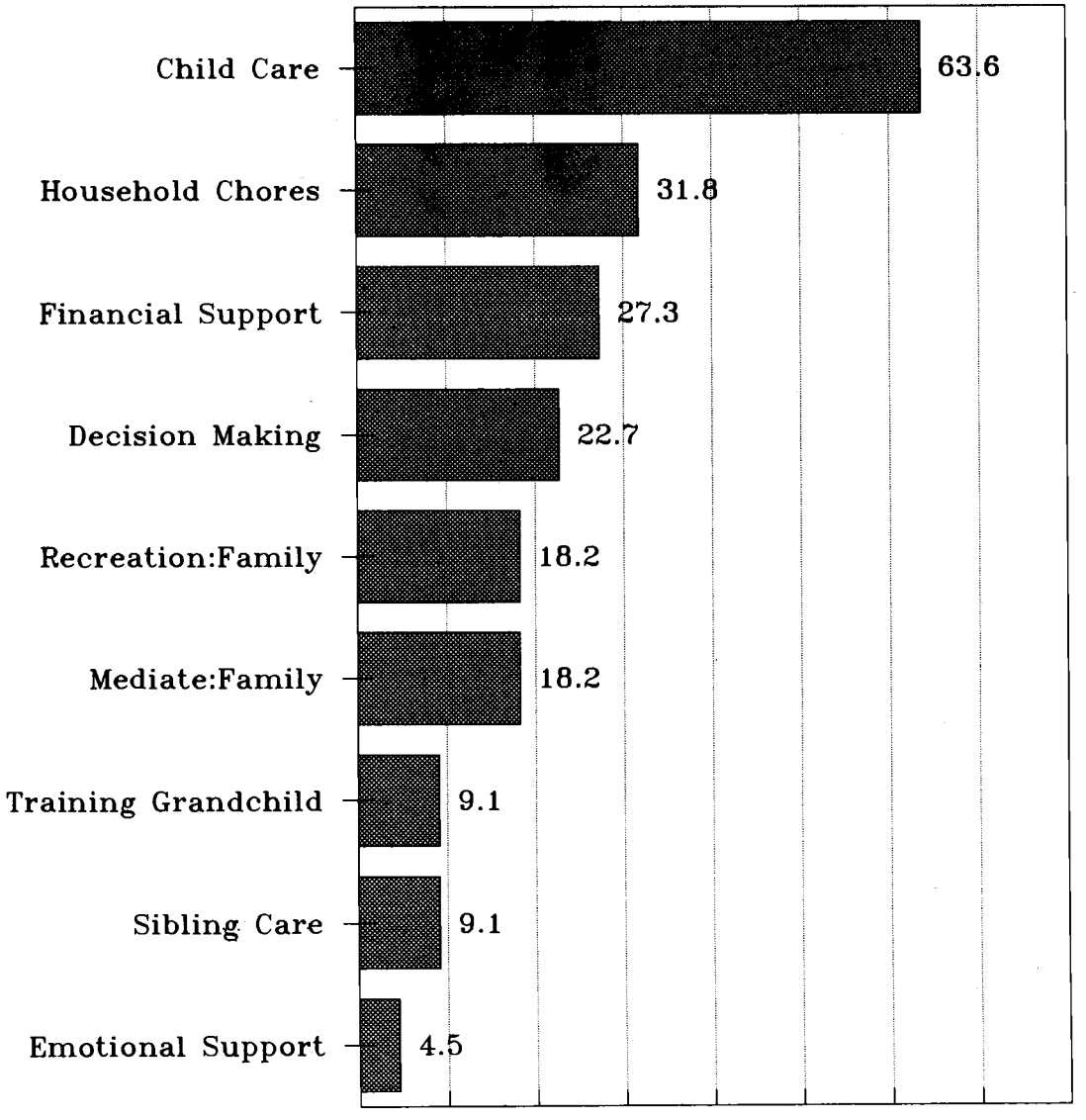

Fig. 7.1
PERCENTAGE ENDORSEMENT OF
SUPPORT BY GRANDPARENTS

The types of support provided by grandparents were analyzed on three variables related to grandparents (sex, age and education) and on three variables related to grandchild (sex, age and level of mental retardation). Analysis of each support domain across the each of these variables is discussed. While interpreting the results unless specifically mentioned, all the references to grandchild refers to the grandchild with mental retardation in the family.

TABLE 7.3
GRANDPARENTS SUPPORT ACROSS GRANDPARENT VARIABLES IN PERCENTAGES

Support	Grandparent Variables					
	Age(Yrs.)		Sex		Education	
	< 65 (n = 13)	> = 65 (n = 9)	G.Mother (n = 16)	G.Father (n = 6)	< = 10 (n = 15)	> 10 (n = 9)
Child Care	69.2	55.6	81.2	16.7	73.3	42.9
Financial Support	7.7	55.6	18.8	50.0	33.3	14.3
Household Chores	23.1	44.4	43.8	0.0	33.3	28.6
Emotional Support	7.7	0.0	6.2	0.0	0.0	14.3
Sibling Care	7.7	11.1	12.5	0.0	13.3	0.0
Decision Making	15.4	33.3	12.5	50.0	26.7	14.3
Training:Child	15.4	0.0	0.0	33.3	0.0	28.6
Reecreation Family	23.1	11.1	0.0	66.7	13.3	28.6
Mediate:Family	23.1	11.1	18.8	16.7	6.7	42.9

Grandparent variables

Analysis of results based on variables related to grandparents (Table 7.3) indicated the following observations that gandparents' nature of support correspond with the traditional female and male roles in our country. Grandmothers were providing more support in the domestic activities like "Household chores", "Child care", etc., whereas grandfathers were providing more instrumental support like "Financial support", providing "Recreation:family", "Decision making", etc.

Emotional support which is considered to be one of the important parental needs which grandparents can meet (Turnbull & Turnbull, 1990) was reported lowest by the grandparents (only 1 grandmother out of the 22 grandparents reported providing such a support).

Results also indicated that if the grandparents were higher educated, they provided greater support in the areas of "Training children", providing "Recreation:family" or "Mediate family" problems and lesser support in all other areas. With respect to age of the grandparents, it was observed that as the age of the grandparents increased, they tended to stay away from providing direct service to their grandchildren with mental retardation such as providing "Child care", "Sibling care", "Training child" and "Recreation:family". However, grandparents over 65 years of the age continued to provide support to the family like "Financial support", assistance in "Household chores" and help in "Decision making".

TABLE 7.4
GRANDPARENTS SUPPORT ACROSS HANDICAPPED CHILD VARIABLES IN PERCENTAGES

Support	Child Variables								
	Age(Yrs.)				Sex		Severity		
	0-6 (n=14)	7-12 (n=2)	13-18 (n=1)	19+ (n=5)	Male (n=10)	Female (n=12)	Mild (n=5)	Moder. (n=13)	Sev-Prof. (n=4)
Child Care	64.3	100.0	0.0	60.0	70.0	58.3	60.0	69.2	50.0
Financial Support	21.4	0.0	100.0	40.0	40.0	16.7	20.0	30.8	25.0
Household Chores	21.4	50.0	0.0	60.0	70.0	0.0	20.0	38.5	25.0
Emotional Support	0.0	0.0	0.0	40.0	10.0	0.0	20.0	0.0	0.0
Sibling Care	7.1	50.0	0.0	0.0	10.0	8.3	20.0	7.7	0.0
Decision making	7.1	0.0	100.0	40.0	20.0	25.0	40.0	15.4	25.0
Training:Child	14.3	0.0	0.0	0.0	0.0	16.7	0.0	15.4	0.0
Recreation Family	28.6	0.0	0.0	0.0	20.0	16.7	0.0	30.8	0.0
Mediate:Family	14.2	0.0	100.0	20.0	0.0	33.3	20.0	7.7	50.0

Handicapped child variables

Results in Table 7.4 strongly indicate that more grandparents offered support if the family had a male grandchild with mental retardation than if the family had a female grandchild with mental retardation. More support from grandparents were provided in areas of "Decision making", "Training child" and "Mediate family conflicts" when the grand child was a female. In all the other areas of support grandparents provided greater support when their grandchild was a male. This indicates the common gender bias towards the male in an Indian society. Most of the support provided to the families occurred when the grandchildren with mental retardation were less than 6 years or when they were over 18 years of age. The results indicate that the grandparents tend to stay with the family when their grandchildren were very young or when their grandchildren were above 18 years. In the first instance, it is possibly the need of the family which makes it necessary for them to stay along with the family whereas in the latter instance it is possibly their own needs due to aging that makes it necessary for them to stay with the family. Hence, the grandparents' support appears to be more available during the early childhood or adult years in the life-cycle of the mentally retarded individual. Firm conclusions, can however, be drawn only based on a study with larger sample.

Grandfathers provided more support to families having children with mild or moderate mental retardation than those families having grandchild with severe to profound mental retardation. This can be attributed to the fact that grandparenting a child with severe to profound mental retardation can evoke strong emotional reactions and inability to manage these strong reactions effectively can result in inability to contribute oneself effectively. Also, grandparenting a child with severe to profound mental retardation pose greater challenges and less hope which could keep grandparents distant from such children.

GRANDPARENTS : IMPACT

Table 7.5 provides definitions of categories related to the impact felt by the grandparents of children with mental retardation.

TABLE 7.5
DESCRIPTION OF GRANDPARENTS IMPACT CATEGORIES

1.	**Concern:Grandchild:** Concerned about condition of grandchild. 'What is wrong with him?' 'Can he grow up to be normal?'
2.	**Feel Ignored:** Less attention from the parents of the index child. 'Our children are too busy to take care of us.' 'We are now a burden to the family.'
3.	**Extra Care: Physical**: Increased responsibilities because of taking care of the grandchild. 'I now have to give him bath and feed him.' 'After doing my daily activities, I find that I've now less time to myself.'
4.	**Emotional Reactions:** Reactions like shock, anger, denial etc. 'I am still shocked. I just can't believe that my grandchild will not be normal.' 'I still feel sad.'
5.	**Worry:Future:** Worried about what is going to happen to the family in the future. 'What will happen to Ram (index grandchild) after his parents are no more? Who will look after him?'
6.	**Financial Strain:** Increased expenses due to birth of the index grandchild. 'Going to doctors for treatment costs lot of money. Initially we didn't mind but now our resources are not like what we used to have.' 'We wanted to take him to Vellore (for treatment) but then we didn't have enough money."
7.	**Increased Trust:God:** Organizing *bhajans* or *kirtans* more frequently at home. 'I spend all of my time singing in praise of God.' 'I pray for a miracle to happen.'

The various types of impacts (in descending order) felt by grandparents in a family having a child with mental retardation are presented in Fig. 7.2.

Data indicate that grandparents experience a wide range of impact because of having a grandchild with mental retardation which includes emotional reactions, worrying about the future of the family, increased physical care responsibilities and increased faith in God. Emotional reactions such as shock, denial, anger and sadness had the strongest impact felt and expressed by grandparents. This is in line with the reported studies in the Western literature (Meyer & Vadasy, 1986; Turnbull & Turnbull, 1990; Ehly, Conoley & Rosenthal, 1985; Pieper, 1976; Mallory, 1981; Hornby & Ashworth,1994; Seligman & Darling, 1989) which have also reported grandparents experiencing immense emotional turmoil because of having a grandchild with disability.

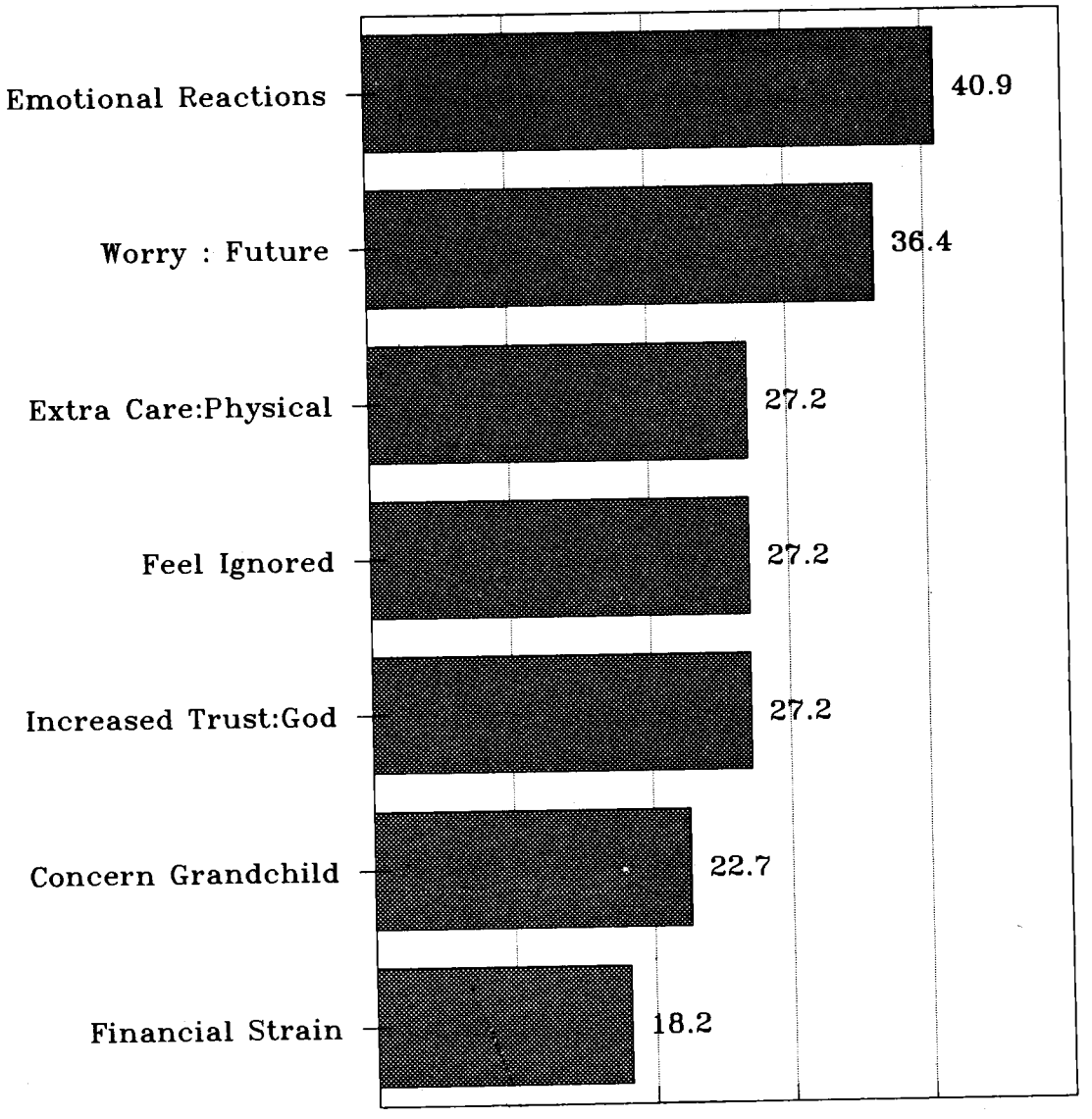

Fig. 7.2
PERCENTAGE ENDORSEMENT OF
IMPACT ON GRANDPARENTS

The types of impact felt by grandparents were analyzed on three variables related to grandparents (sex, age and education) and handicapped child (sex, age and level of mental retardation). Analysis of impact felt by grandparents across these variables is presented.

TABLE 7.6
IMPACT ON GRANDPARENTS ACROSS GRANDPARENT VARIABLES IN PERCENTAGES

Impact : Categories	Grandparent Variables					
	Age(Yrs.)		Sex		Education	
	< 65 (n = 13)	> = 65 (n = 9)	G.Mother (n = 16)	G.Father (n = 6)	< = 10 (n = 15)	> 10 (n = 7)
Concern:Grandchild	7.7	44.4	31.2	0.0	20.0	28.6
Feel ignored	23.1	33.3	31.2	16.7	26.7	28.6
Extra care physical	23.1	33.3	37.5	0.0	26.7	28.6
Emotional : reactions	30.8	55.5	37.5	50.0	53.3	14.3
Worry : future	53.8	11.1	31.2	50.0	26.7	57.1
Financial Strain	7.7	33.3	12.5	33.3	26.7	0.0
Increased Trust : God	7.7	55.5	31.2	16.7	33.3	14.3

Grandparents variables

Analysis of results based on **grandparents variables** (Table 7.6) indicated that grandparents do get strongly affected because of having a grandchild with mental retardation. Grandparenting a child with mental retardation does evoke strong emotional reactions in grandparents. The "emotional reactions" are seen to be more in grandfathers than in grandmothers. Grandfathers seem to be affected more with the "financial strain" and "worry future" of the grandchild. In contrast only grandmothers seem to experience the impact of having to provide "extra care; physical". Hence, the added responsibility of looking after the physical needs of the grandchild is solely borne by the grandmothers. Also it was only the grandmothers who reported "concern; grandchild", i.e., looking for cures. Grandmothers also reported greater "increased trust: God".

The global impact seen is greater in higher educated grandparents than less educated grandparents. However, the less educated grandparents had greater impact with regard to "emotional reaction", "financial strain" and "increased trust: God".

With regard to age, greater impact is seen in grandparents above 65 years of age except for "worry future" which is reported to be more by grandparents less than 65 years of age.

TABLE 7.7
IMPACT ON GRANDPARENTS ACROSS HANDICAPPED CHILD VARIABLES IN PERCENTAGES

Impact : Categories	Handicapped Child Variables								
	Age(Yrs.)				Sex		Severity		
	0-6 (n=14)	7-12 (n=2)	13-18 (n=1)	19+ (n=5)	Male (n=10)	Female (n=12)	Mild (n=5)	Moder. (n=13)	Sev-Prof. (n=4)
Concern:Grandchild	14.3	0.0	0.0	60.0	30.0	16.7	20.0	23.1	25.0
Feel ignored	21.4	50.0	0.0	40.0	40.0	16.7	20.0	23.1	50.0
Extra care physical	21.4	50.0	100.0	20.0	30.0	25.0	40.0	15.4	50.0
Emotional Reactions	21.4	100.0	0.0	80.0	70.0	16.7	40.0	46.2	25.0
Worry : future	57.1	0.0	0.0	0.0	10.0	58.3	40.0	38.5	25.0
Financial Strain	21.4	0.0	100.0	0.0	30.0	8.3	0.0	23.1	25.0
Increased Trust : God	14.3	0.0	100.0	60.0	40.0	16.7	20.0	30.8	25.0

Handicapped child variables

Results as shown in Table 7.7 strongly indicate that the grandparents start "worry; future" of their grandchild the moment they come to realize that their grandchild has mental retardation even if the child is very young. Except for greater "worry; future" of the granddaughter with mental retardation in comparison to the grandson, grandparents seem to be more impacted because of the presence of grandson with mental retardation as "Concern:grandchild", "Feel: ignored", "Extra care: physical", "Emotional reactions", "Financial strain" and "Increased trust: God" has been reported more by grandparents having grandsons with mental retardation.

The global impact is seen to be greater as the severity of mental retardation in grandchild increased except in the impact areas such as "Emotional reactions" and "Worry: future" which was seen to be more in the presence of grandson with mild or moderate mental retardation. Firm conclusions can however, be only drawn based on a study with larger sample.

GRANDPARENTS : NEEDS

Table 7.8 provides definitions of categories related to the needs reported by grandparents of children with mental retardation.

TABLE 7.8

DESCRIPTION OF GRANDPARENTS NEEDS IN CATEGORIES

1.	**Cure: Mental Retardation :** Looking for a treatment or a therapy that will cure mental retardation 'I wish he becomes normal'. 'There should be some medicines to cure him'.
2.	**Guidance : Help Family:** Guidance from therapists as to how they can help the family. 'I wish I could do something for the child. My daughter-in-law doesn't allow me to come near the child?' 'Are there any professionals who can guide us how to work effectively within the family in taking care of the child?'
3.	**Information : Government Benefits :** From where and what are the benefits available from the Government for such children. 'Can't the government take care of these children?' 'Does the government provide any help to these children? From whom can we get this information?'
4.	**Care: Future :** Future social security of the grandchild. 'How can we provide a stable and strong security for the child when their parents are no more?' 'Are there any government programmes to look into long term care of these children?'
5.	**Information : Child Management :** Availability of training programmes to help them manage their grandchild. 'How can we train our grandchild so that he becomes independent?' 'Are there any training strategies to help my grandchild become independent in his or her daily activities?'
6.	**Training Communication :** Training programs in language and communication for the grandchild. 'Can he talk eventually?' 'I'll be happy if he can indicate his basic needs independently'.
7.	**Cause : Mental Retardation :** Interested to know what caused the condition. 'What caused this condition ? Will my other daughters be also affected?'

8. **Sensitivity : Professionals :** Want the professionals to be more sensitive in working with the family and grandparents in general.
   'I hope the professionals are little more considerate to us when they are working with us?'
   'The professionals don't listen to us'.
9. **Information : Resources:** From whom and where to turn for help.
   'We want him to go school. Which school should he go to?'
   'Who are the professionals we should contact?'

The various types of needs in descending order expressed by grandparents in a family having a child with mental retardation are presented in Fig. 7.3

Data indicated that grandparents expressed a wide variety of needs. The most strongly felt need of grandparents was the need for imparting "training: communication", followed by "Cure: mental retardation", "Information: resources", "Care: future", "Information: child management", "Sensitivity: professional", "Guidance: help family", "Cause: mental retardation" and "Information: Government benefits". "Cause: mental retardation" and "Information: Government benefits" was ranked lowest in the list of expressed needs.

The types of needs expressed by grandparents were analyzed on three variables related to grandparents (sex, age and education level) and grandchild (sex, age and level of mental retardation). Analysis of needs expressed by grandparents across the variables of sex, age and education is discussed.

Grandparent variables

The results as shown in Table 7.9 indicate that the needs expressed by grandparents are all directed to helping the grandchild and his/her family. None of the needs expressed by grandparents were self oriented. This is an indication of possibly the strength of the Indian family where in a crisis, self needs are kept aside in preference to the general welfare of the family. The family comes first than self.

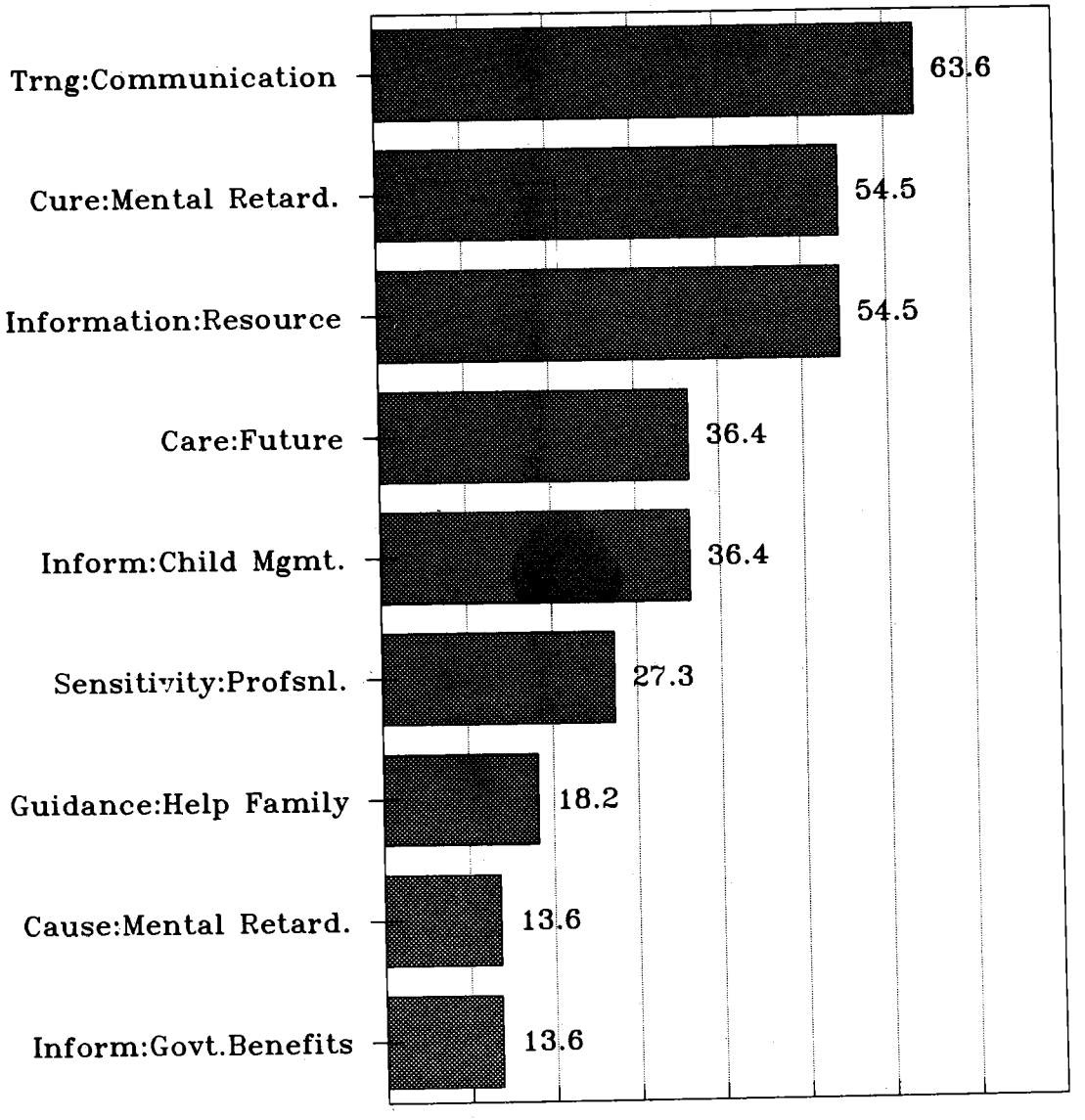

Fig. 7.3
PERCENTAGE ENDORSEMENT OF
GRANDPARENTS NEEDS

TABLE 7.9
NEEDS OF GRANDPARENTS ACROSS GRANDPARENT VARIABLES IN PERCENTAGES

Needs	Grandparent Variables					
	Age(Yrs.)		Sex		Education	
	< 65 (n = 13)	> = 65 (n = 9)	G.Mother (n = 16)	G.Father (n = 6)	< 10 (n = 15)	> 10 (n = 7)
Cure:Mental Reatardation	53.8	55.6	56.2	50.0	60.0	42.9
Guidance:help family	23.1	11.1	18.8	16.7	13.3	28.6
Information:Govt. benefits	0.0	33.3	12.5	16.7	13.3	14.3
Care:future	15.4	66.7	37.5	33.3	40.0	28.6
Information:child management	38.5	33.3	43.8	16.7	26.7	57.1
Training:Communication	61.5	66.7	50.0	100.0	53.3	85.7
Cause:mental retardation	23.1	0.0	6.2	33.3	0.0	42.1
Sensitivity:Professionals	38.5	11.1	25.0	33.3	26.6	28.6
Information:resources	38.5	66.7	50.0	66.7	66.7	28.6

Results also showed that majority of the needs expressed by grandmothers as compared to grandfathers were related to directly helping the child and the family which included "Cure: mental retardation", "Guidance: help family", "Care: future" and "Information: child management". However, majority of needs expressed by grandfathers related to seeking information or locating services such as "Information: Government benefits", "Training: communication", "Cause: mental retardation", "Sensitivity: professional" and "Information: results". This goes with the traditional outdoor-indoor roles of males and females and the patriarchal society system in India where fathers take the role of decision making leaving the household reins to the mothers.

Grandparents belonging to below 65 years of age expressed greater needs in "Guidance: help family", "Information: child management", "Cause: mental retardation" and "Sensitivity: professionals". This can be explained by the fact that during the early years of grandchild's life and while still they have more energy, the grandparents do seek information about their grandchild's condition which they do not seemed to be received effectively from professionals.

Grandparents above the age of 65 years however, seem to express greater needs especially in the areas of "Care:future", "Training: communication", "Information: resources". Analysis in relation to the education of grandparents indicate that higher educated grandparents in comparison with lesser educated grandparents expressed greater needs in "Guidance: help family", "Information: Government benefits", "Information: child management", "Training: communication", "Cause: mental retardation" and "Sensitivity: professionals". Less educated grandparents however expressed greater needs in the areas of "Cure: mental retardation", "Care: future" and "Information: resources". Grandparents irrespective of education, i.e., somewhat equally expressed the need for professionals to be more sensitive and empathetic in their attitudes.

TABLE 7.10
NEEDS OF GRANDPARENTS ACROSS HANDICAPPED CHILD VARIABLES IN PERCENTAGES

Needs	Handicapped Child Variables								
	Age(Yrs.)				Sex		Severity		
	0-6 (n=14)	7-12 (n=2)	13-18 (n=1)	19+ (n=5)	Male (n=10)	Female (n=12)	Mild (n=5)	Moder. (n=13)	Sev-Prof. (n=4)
Cure : Mental Retardation	71.4	0.0	100.0	20.0	50.0	58.3	40.0	53.8	75.0
Guidance : Help Family	21.4	0.0	0.0	20.0	20.0	16.7	20.0	23.1	0.0
Information : Govt. Benefits	0.0	0.0	100.0	40.0	20.0	8.3	20.0	7.7	25.0
Care : Future	35.7	0.0	100.0	40.0	50.0	25.0	0.0	46.2	50.0
Information : Child Management	42.9	0.0	0.0	40.0	40.0	33.3	20.0	38.5	50.0
Training : Communication	57.1	50.0	0.0	100.0	80.0	50.0	60.0	69.2	75.0
Cause : Mental Retardation	14.3	0.0	0.0	20.0	0.0	25.0	20.0	15.4	0.0
Sensitivity : Profes-sionals	28.6	0.0	0.0	40.0	50.0	8.3	40.0	30.8	0.0
Information : Resources	50.0	100.0	100.0	40.0	70.0	41.7	40.0	61.5	50.0

Handicapped Child Variables

Analysis of results as shown in Table 7.10 based on handicapped grand child variables indicated grandparents having grandchildren below 6 years of age or 19 years and above expressed greater number of needs. The number of (n) grandparents within the age groups of grandchildren is so less especially between 7-12 years (n=2) and 13-18 years (n=1) to justify any further interpretation. More grandparents having a male grandchild on the whole endorsed greater needs. This also is consistent with the observation that the grandparents having a male grandchild are more involved with the family. Grandparents having male grandchildren with mental retardation perceived greater needs such as "Guidance: help family", "Information: Government benefits", "Care: future", "Information: child management", "Training: communication", "Sensitivity: professionals" and "Information: resources". "Cure: mental retardation", "Cause: mental retardation" are the only two needs expressed higher by grandparents having grand daughters with mental retardation.

Grandparents having grandchildren with severe and profound mental retardation reported greater needs in the areas of "Cure: mental retardation", "Information: government benefits", "Care: future", "Information: child management" and "Training: communication". Grandparents having grandchildren with moderate mental retardation expressed greater needs in the areas of "Guidance: help family", and "Information: resources" while grandparents having grandchildren with mild mental retardation reported greater needs in the area of "Sensitivity: professionals" only. Since children with severe and profound mental retardation do pose greater challenges for obvious reasons, grandparents having grandchildren with severe and profound mental retardation have largely expressed greater needs than grandparents having grandchildren with mild or moderate mental retardation.

IMPLICATIONS FOR SERVICE PROVIDERS

Any work on the families would be incomplete without taking into account the role of grandparents. This chapter provided a profile of support provided, the impact felt and the needs expressed by 22 grandparents from 18 families having a grandchild with mental retardation. The study reflects certain messages for the service providers which are quite loud and clear.

- Grandparents are a great natural resource/support for the families having persons with mental retardation and hence their role needs to be strengthened. It has been reported by parents (see chapter 5) that acceptance and support by grandparents especially paternal grandparents is considered as an important facilitator in coping.

- Grandparents are involved in many ways in providing support to the family yet they have expressed the need for further help and guidance from professionals as to how they can contribute better which must be met.

- Grandparents do get affected in many ways because of having a grandchild with mental retardation. Help in mitigating such effects must start early with grandparents and strategies for help included in the family intervention programmes.

- Grandparents though have reported emotional reactions as the strongest impact, yet, while expressing needs they didn't seek any help for the same. The need to resolve or understand these emotional reactions could be explored if necessary during counselling programmes.

- Grandparents too have several needs because of having a grandchild with mental retardation in the family. These needs require to be identified and individualized intervention programmes have to be worked out to meet such needs.

- All the family members including the parents and siblings of the child with mental retardation must become aware of the grandparents needs and involve themselves in meeting the grandparents needs. When professionals work towards mitigating the impact and help meeting the needs of grandparents, it would help strengthen grandparents to involve more constructively to the well being of the grandchild with mental retardation and the whole family. Family counselling would go a long way in meeting some of the needs.

- Grandparents could be brought together in a group to share their concerns with each other. Interactions amongst affected grandparents could contribute immensely in resolving emotional reactions and learning from each other's experience in coping with certain common situations.

- Professionals working and interacting with the families do need to equip themselves with effective counselling skills to communicate the child's condition and also to have better relationships with all the family members.
- Training programmes for the grandparents could be conducted as per identified needs of grandparents. This would equip them with the knowledge and skills and enable grandparents to spend time with their grandchild more usefully and effectively.

SOME FURTHER RESEARCH INDICATIONS

Few suggestions for further research are presented below:

- The findings on support, impact and needs of grandparents are based on a sample of only 22 grandparents having grandchild with mental retardation and living with the affected family. To draw firm and reliable conclusions studies need to be conducted on a larger sample.
- More systematic and detailed research is required to identify all the variables affecting grandparents, to verify the effect of these variables on grandparenting and to verify the significance of these variables across generations.
- The method of obtaining information on the nature of support, impact and needs was through the use of open ended questions. Hence, reporting of certain information could have been missed by grandparents. Other methods of obtaining such information could be used to ensure that no information is missed out from reporting. Use of NIMH-FAMNS(Grandparents) which is an outcome of the study could be used for obtaining comprehensive information.
- Present research was only focused on grandparents living with the family. It would be useful to find out how the grandparents even though living away from the affected families feel the impact, what support if any, they are providing to the affected family and their nature of needs if they are different from grandparents living with the family.
- In the present study, grandparents of only 18 families out of the 120 families were identified as living with the family. As we know that grandparents

could be a great source of support to the affected family, it would be useful to study the factors which keep grandparents away from such families.

CONCLUSION

This chapter has brought to focus the necessity to identify the strengths and needs of grandparents and target intervention programmes which would aim at supporting the entire family including grandparents rather than the child with mental retardation alone. Such an approach would help professionals to get a clear perspective as to how families function on a day to day basis and help utilise and strengthen the existing resources for the betterment of the "whole family ".

REFERENCES

Bell, C.(1968). **Middle-class families.** London: Routledge and Kegan Paul.

Boyd, R.R. (1969). **The valued grandparent: A changing social role.** In W.T. Donahue, J.L. Kornbluh & B. Power (Eds), Living in a multigenerational family. Ann Arbor:Institute of Gerontology, University of Michigan.

Ehly, S.W., Conoley, J.C., & Rosenthal, D. (1985). **Working with parents of exceptional children.** St. Louis. Times Mirror.

Hornby, G. & Ashworth,T. (1994). **Grandparent support for families who have children with disabilities: A survey of parents.** Journal of Child and Family Studies (in press).

Mallory, B. (1981). **The impact of public policies on families with young handicapped children.** Topics in Early Childhood Special Education, 1 (3), 77.

Meyer, D.J., & Vadasy, P.F. (1986). **Grandparents workshops: How to organize workshops for grandparents of children with handicaps.** Seattle: University of Washington Press.

Pieper, E. (1976). **Grandparents can help.** Exceptional Parent, 6, 7-10.

Radcliffe-Brown, A.R. (1952). **Structure and function in primitive society.** London: Cohen & West.

Robertson, J.F. (1977). **Grandmotherhood: A study of role perceptions.** Journal of Marriage and the Family, 39, 165-174.

Schorr, A. (1960). **Filial responsibility in the modern American Family.** Washington D.C: U.S. Department of Health, Education and Welfare.

Seligman, M., & Darling, R.B. (1989). **Ordinary families, special children: A systems approach to childhood disability.** New York. Guilford Press.

Shanas, E. (1967). **Family help patterns and social class in three countries.** Journal of Marriage and the Family, 29, 257-266.

Sonneck, I.M., (1983). **The maternal grandmother role in families with young handicapped children.** Unpublished doctoral dissertation, Bloomington, Indiana University.

Sussman, M.B. (1953). **The help pattern in the middle class family.** American Sociological Review, 18, 22-28.

Townsend, P. (1957). **The family life of old people in East London.** London: Routledge and Kegan Paul.

Turnbull, A.P., & Turnbull, H.R. (1990). **Families, professionals and exceptionality: A special partnership.** Columbus, OH. Charles Merrill.

CHAPTER 8

Need Based Family Intervention Model

INTRODUCTION

Consider the following statements made by some of the parents having mentally retarded children;

"We are only keen to know how we should handle our child's behaviour and train him. But every time we come for consultations the focus is on our relationships with each other rather than telling us what to do with this child. I must tell you we are a very happy couple and we have no problems with each other. Can you help us?"

"I am given all the programmes to carry them out at home. If you permit me to frankly tell you, professionals think that they have done their duty by giving us the program, that is what actually they are paid for, should they not think that we also have to do justice to our jobs for which we are paid? At the end of the day when we are not able to do full justice with the program we feel very guilty."

"I don't mind doing hard work or slogging the whole day for my children. I also don't mind if my husband does not share house work with me because I think he is too busy with his business and I should lookafter the house and

children because I stay in the house. What actually depresses me most is that my husband does not even acknowledge that I am doing so much. He remains so indifferent."

The views and remarks of the parents quoted above highlight strongly the need to review the services which are presently being offered to the mentally retarded individuals and the affected families. If we plan to make the services more meaningful to the population we serve which essentially involves the mentally retarded individual and the family, the following points deserve to be given a serious thought.

(a) Do the present models of services available match all the needs of the families? (For family needs see chapters 4,6,7)

(b) Are the needs of the families assessed before providing them with the needful services?

(c) Are the services which meet family needs made available to all the families?

(d) Have any attempts been made so far to evaluate the services keeping the needs of families in perspective?

(e) Are the service providers prepared with required competencies to meet the multivarious needs of families having mentally retarded individuals?

With the present models of service provision available in our country surely, the answer to all the above stated questions is not very encouraging.

Though there is much talk about involving parents in the training programs of mentally retarded children and conducting parent training programs still the programs continue to be predominantly child - oriented. To aim at conducting need based family intervention programs, the needs of the different family members would have to be assessed. Based on the goals and priorities set in consultation with the family members focused intervention programs need to be implemented and evaluated.

Assessing family needs: Implications

Analysing information from the available research literature on assessing needs of families having mentally retarded individuals (Dunst and Leet, 1987., Dunst and Trivette, 1985., Dunst, Vance & Cooper, 1986) the following is strongly indicated.

- Unmet needs affect the well being and interfere with implementation of professionally prescribed regimens.
- The greater the number of unmet needs, the greater the number of emotional and physical problems reported by parents of mentally retarded children which includes stress, negative feelings towards the child, alienation between parent and help giver.
- The greater the number of needs unrelated to child-level interventions, the greater the probability that the parents indicate that they do not have the time, energy and personal investment to carry out such interventions.
- Before parents are asked to carry out professionally prescribed interventions efforts must be made to meet other family - identified needs.

NIMH-FAMNS AND NEED BASED FAMILY INTERVENTION MODEL

To encourage family intervention programs, Need based family intervention model is introduced. This model is essentially based on the empirical understanding of the families presented in the preceding chapters as also combined with nearly 20 years of experience of working with families having mentally retarded individuals. NIMH-Family needs schedule (NIMH-FAMNS) is the basis and is recommended to be used before applying the "Need based family intervention model". Details on development of NIMH-FAMNS is included in Chapter 3. It is logical to assess the needs before planning and implementing family intervention programs. It is important to keep in mind that needs vary from individual to individual and can vary for the same individual at different periods of time. Hence, the interventions also are required to be individualised based upon the identified individual needs.

NIMH Family Needs Schedule

The final version of NIMH-FAMNS is now presented (for details on development of NIMH-FAMNS, see chapter 3) which would enable the user to assess the needs of mothers, fathers, sisters, brothers, grandmothers and grandfathers of mentally retarded individuals. It is recomended that the introduction guidelines for administration and scoring must be understood before the actual use of NIMH-FAMNS with the family.

NIMH FAMILY NEEDS SCHEDULE (NIMH-FAMNS)

Authors

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INTRODUCTION

NIMH Family Needs Schedule (NIMH-FAMNS) was developed as part of the multi-centred project "Strengthening Families: Identifying and meeting information needs of families having individuals with mental retardation" funded by the National Institute for the Mentally handicapped, Secunderabad in the year 1993 . A semi structured interview schedule (NIMH-FAMNS) was developed which could be used for the following purposes:

(1) To identify present needs of the Indian families having mentally retarded individuals,

(2) To prioritise the needs for family intervention.

(3) To objectively evaluate family intervention programmes.

NIMH-FAMNS consists of three schedules

(1) NIMH FAMILY NEEDS SCHEDULE (Parents)

(2) NIMH FAMILY NEEDS SCHEDULE (Sibings)

(3) NIMH FAMILY NEEDS SCHEDULE (Grandparents)

The Schedule was developed using scientific steps. The pilot study to identify the needs of the family members was carried out on 20 families. The final study was conducted on a sample of 120 families. The sample was drawn

from four centres based in Secunderabad, Bhopal, Trivandrum and New Delhi. These families represented all cross-sections of low, middle and high socio-economic strata; nuclear and non-nuclear families, urban and non-urban areas. As regards characteristics of children with mental retardation, sample was drawn from all levels of severity and divided in age groups of below 6 years, 7-12 years, 13-18 years and 19 years and above. Thus, an effort was made to identify needs of families including, mothers, fathers, brothers, sisters, grandmothers, grandfathers having diverse socio-economic backgrounds from four different cities having children with mental retardation at different ages and severity levels.

GUIDELINES FOR ADMINISTRATION AND SCORING OF NIMH-FAMNS

It is recommended that the interviewer be trained in "clinical interview method" before using NIMH-FAMNS. However, this need not be followed as a strict rule.

The following guidelines need to be strictly adhered to by the interviewer.

(1) The interviewer should be familiar with the family members and the index child with mental retardation to be interviewed to an extent that the respective family members feel comfortable to share their concerns with the interviewer. Hence adequate rapport with the family members is essential before starting to use NIMH-FAMNS.

(2) The interviewer before starting to use NIMH-FAMNS must inform the concerned respondent that he/she would be asking certain specific questions to understand their present needs because of having a mentally retarded child in the family.

(3) Consent must be taken to interview each of the respondents seperately. Joint interviews with both parents or other respondents should be undertaken only if family members resist giving independent interviews.

(4) The questions included in **NIMH-FAMNS** should be asked in the same sequential order.

(5) Each question should be asked in such a way that the interviewer does not influence the decision of the concerned respondent.

(6) Wherever the word "Child", "Your Child", "Sibling" or "Grandchild" occurs in the questions included in NIMH-FAMNS the interviewer should replace it with the index mentally retarded child's name.

(7) Use the "remarks" Column to enter qualitative impressions of concerned family members wherever indicated.

(8) For each question on NIMH-FAMNS the interviewer must obtain rating from the concerned respondent and enter the score in the appropriate **A** or **B** column. Pre-intervention scores should be entered in column **A** and post-intervention scores under column **B**. The following scoring patterns should be followed :

Enter **2**, if the respondent endorses the particular need item as "**Very much**".

Enter **1**, if the respondent endorses the particular need item as "**Little**".

Enter **0**, if the respondent endorses the particular need item as "**No Need**".

(9) Enter the total scores of each of the AREAS as also the grand total scores obtained by the respondent on NIMH-FAMNS at the appropriate places provided in the schedule.

(10) Complete the parent needs profile after completing NIMH-FAMNS (Parents)

(11) Select and write goals for family intervention at appropriate places provided in the schedule in consultation with the family members.

(12) Use seperate NIMH-FAMNS schedule for each member of the family.

NATIONAL INSTITUTE FOR THE MENTALLY HANDICAPPED

FAMILY NEEDS SCHEDULE

IDENTIFICATION DATA SHEET

Name of the Interviewer :

Position held :

Name of the Institute :

Date :

CHILD CHARACTERISTICS

Name :

Age :

Sex :

Level of Mental Retardation :

FAMILY CHARACTERISTICS

Total family income :

Type of family : Nuclear/non-nuclear

Family status : Intact/broken

Address and Telephone No. :

NIMH FAMILY NEEDS SCHEDULE (Parents)
NIMH-FAMNS(Parents)

RESPONDENT CHARACTERISTICS DATE : _____

Name:

Relationship with the index child : Mother/Father

Age: Education: Occupation:

Address for correspondence :

Scoring : ENTER 2 IF NEED IS "VERY MUCH" A PRE-INTERVENTION SCORES

ENTER 1 IF NEED IS "LITTLE" B POST-INTERVENTION SCORES

ENTER 0 IF NEED IS "NO NEED"

AREAS/Needs	Scoring		Remarks
	A	B	
AREA I - INFORMATION - CONDITION			
1. Do you need information about your child's condition or disability?			
2. Do you need information on assessment reports of your child?			
3. Do you need information on what your child will be able to do/ and will not be able to do ?			
4. Do you need help in identifying child's present characteristics/ features which may have negative effects in the future?			
5. Do you need reading materials related to your child's condition ?			
6. Do you need information on nutrition /special diet for your child?			
AREA - I TOTAL SCORE			
AREA II - CHILD MANAGEMENT			
7. Do you need information about normal child growth and development ?			
8. Do you need information on how to bring up your child ?			
9. Do you need help to discipline /handle your child ?			
10. Do you need help in managing behaviour problems or difficult behaviours in your child ?			
11. Do you need help in getting your child to cooperate in his/her daily activities ?			
12. Do you need to know about what teachers/ trainers are teaching / training your child ?			
13. Do you need to talk with your child's teacher / trainer ? (How often)			
14. Do you need help in deciding to plan for another child ?			
AREA - II TOTAL SCORE			

AREAS/Needs	Scoring		Remarks
AREA III - FACILITATING INTERACTION	**A**	**B**	
15. Do you need information on how to explain your child's condition to (Specify) (a) Spouse			
(b) Other sibling's			
(c) Significant other members in the family			
(d) Neighbours and friends			
(e) Others			
16. Do you need help to involve others in meeting service needs of your child ? (Specify) (a) Spouse			
(b) Sibling's			
(c) Grandparents			
(d) Significant other members in the family			
(e) Others			
AREA - III TOTAL SCORE			
AREA IV - SERVICES			
17. Do you need information on the services that are presently available for your child ?			
18. Do you need help in deciding which training centre/ school to admit your child ?			
19. Do you need information from where to procure training materials for your child ?			
20. Do you need professionals who could visit your home and train your child ?(how often) Daily/ Thrice a week / Weekly/ Monthly.			
21. Do you need information on the effect of admitting your child to special /normal regular school ?			
AREA - IV TOTAL SCORE			
AREA V - VOCATIONAL PLANNING			
22. Do you need help in finding the most appropriate vocation for your child?			
AREA - V TOTAL SCORE			
AREA VI - SEXUALITY			
23. Do you need information on sexuality issues related to your child ?			
AREA - VI TOTAL SCORE			
AREA VII - MARRIAGE			
24. Do you need information to marriage issues related to your child?			
AREA - VII TOTAL SCORE			
AREA VIII - HOSTEL			
25. Do you need help in deciding whether to admit or not to admit your child in a hostel?			
26. If you have decided to place your child in a hostel, do you need information which hostel you should admit your child ?			
AREA - VIII TOTAL SCORE			
AREA IX - PERSONAL - EMOTIONAL			
27. Do you need to have more time to self ?			

AREAS/Needs	Scoring		Remarks
	A	B	
28. Do you need to talk to someone about your personal problems?			
29. Do you need help when you are worried, feel sad or depressed ?			
30. Do you need help to manage your physical health problems ?			
AREA - IX TOTAL SCORE			
AREA X - PERSONAL - SOCIAL			
31.Do you need to have more friends with whom you can discuss/ share joys and sorrows ?			
32. Do you need to meet and discuss with parents having children with similar conditions ?			
AREA - X TOTAL SCORE			
AREA XI - SUPPORT - PHYSICAL			
33. Do you need transportation to take your child from home to school/ service centre/ training centre and back ?			
34. Do you need somebody to drop and bring back your child from school/ training centre/ service centre?			
35. Do you need someone/ worker to look after your child at home ?(Specify how often) Daily/ Occasionally/ Part time/ Full time			
AREA - XI TOTAL SCORE			
AREA XII - FINANCIAL			
36. Do you need financial help to pay for medical care, medicine, therapy, or any other services your child needs?			
37. Do you need financial help to purchase training materials for your child ?			
38. Do you need financial help for meeting any other needs of your child ? (Specify) (a)			
(b)			
(c)			
(d)			
AREA - XII TOTAL SCORE			
AREA XIII - FAMILY RELATIONSHIPS			
39. Do you need help in discussing family problems and finding solutions ? (Specify) (a) With spouse			
(b) Parent child			
(c) Between sibling's			
(d) With other significant family members			
40. Do you need information as to how your child with mental retardation could effect children ?			
AREA - XIII TOTAL SCORE			
AREA XIV - FUTURE PLANNING			
41. Do you need help in financial planning for your child training and vocational aspects ?			

AREAS/Needs	Scoring		Remarks
	A	B	
42. Do you need information on how to transfer your property /savings accounts/ pensionary benefits to your child after your death ?			
AREA - XIV TOTAL SCORE			
AREA XV - GOVERNMENT BENEFITS AND LEGISLATION			
44. Do you need information on various government benefits for persons with mental retardation and their families ?			
45. Do you need information on the legislation for persons with mental retardation ?			
AREA - XV TOTAL SCORE			

NIMH-FAMNS(Parents)

GOALS FOR INTERVENTION WITH PARENTS

Child's Name : Date:

Parent's Name :

Relationship with child : Mother/Father

GOALS :

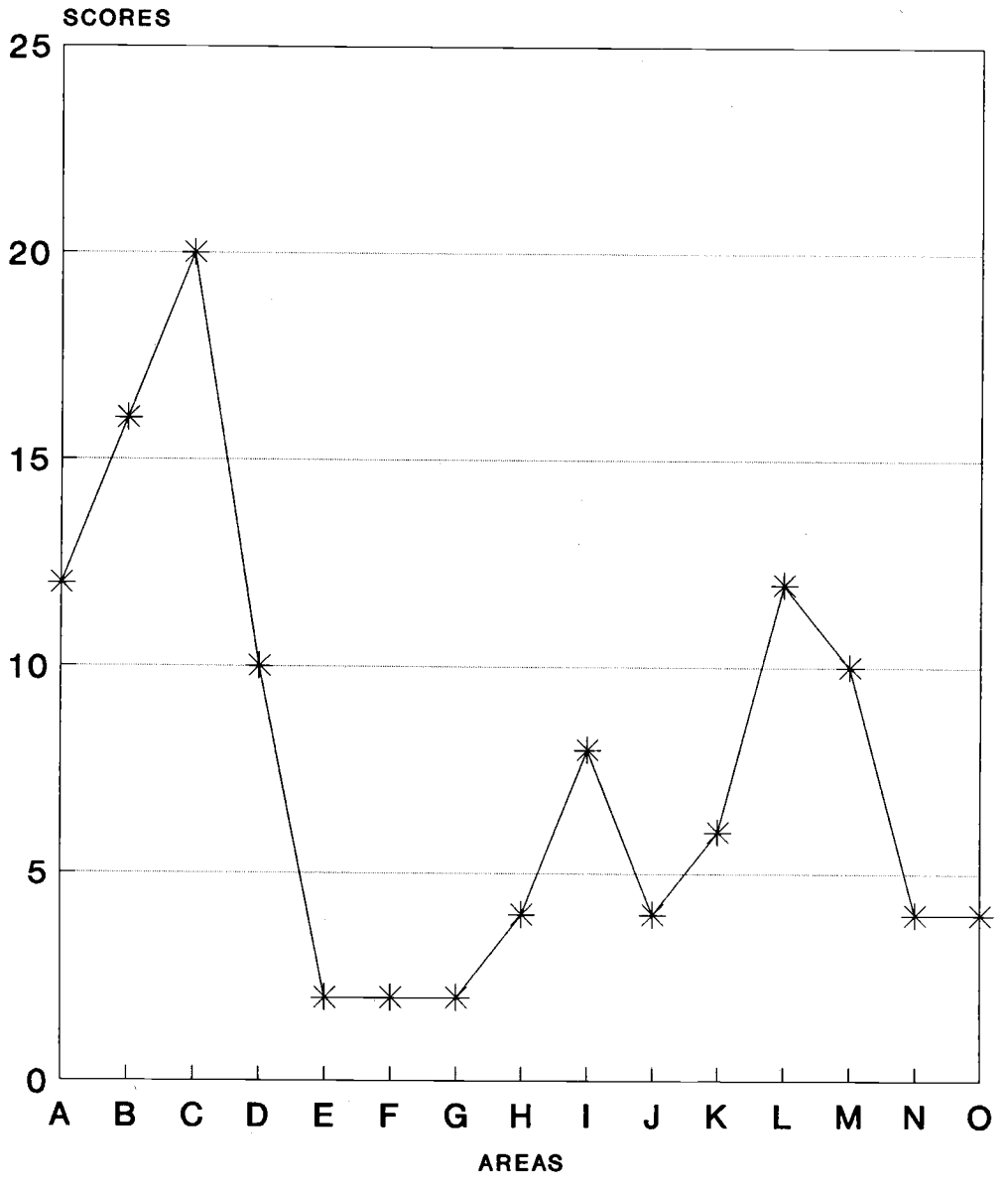
NIMH-FAMNS (Parents)
Parent Needs Profile

Parent's Name : _____ Child's Name : _____
(Mother/Father)

AREAS	Total possible Scores	Obtained Score Dt: A*	Dt: B*
1. Information Condition	12		
2. Child Management	16		
3. Facilitating Interaction	20		
4. Services	10		
5. Vocational Planning	02		
6. Sexuality	02		
7. Marriage	02		
8. Hostel	04		
9. Personal - Emotional	08		
10. Personal - Social	04		
11. Support - Physical	06		
12. Financial	12		
13. Family Relationships	10		
14. Future Planning	04		
15. Government Benefits & Legislation	04		
NIMH-FAMNS (Parents) Grand Total Scores	**116**		

A* PRE-INTERVENTION SCORES
B* POST-INTERVENTION SCORES

NIMH FAMNS (Parents)
PARENT NEEDS PROFILE



A: PRE-INTERVENTION
B: POST-INTERVENTION

NIMH FAMILY NEEDS SCHEDULE (Siblings)
NIMH-FAMNS(Siblings)

RESPONDENT CHARACTERISTICS DATE : __ _____

Name:

Relationship with the index child : Brother/Sister

Age: Education: Occupation:

Address for correspondence :

Scoring : ENTER 2 IF NEED IS "VERY MUCH" A PRE-INTERVENTION SCORES
ENTER 1 IF NEED IS "LITTLE" B POST-INTERVENTION SCORES
ENTER 0 IF NEED IS "NO NEED"

NEEDS	Scoring		Remarks
	A	B	
1. Do you need information about your sibling's condition or disability ?			
2. Do you need information on what your sibling will be able to do/ and will not be able to do ?			
3. Do you need information on how to manage your sibling's ? (Specify) (a) Problem behaviours			
(b) Skill training			
(c) Vocational training			
(d) Any other			
4. Do you need information for the following : (a) Professionals for meeting specific needs of sibling			
(b) Availability of services			
(c) Training materials			
(d) Any others			
5. Do you need information on how to explain your sibling's condition to others ? (Specify) (a) Your spouse			
(b) Other sibling's			
(c) Significant others in the family			
(d) Neighbours			
(e) Friends			
(f) Any other			
6. Do you need information about programmes organized for the non-handicapped siblings for rehabilitation of persons with mental retardation ?			
7. Do you need help in deciding whether to admit or not to admit your sibling with mental retardation in a hostel			
8. Do you need more time to self ? (Specify) (a) To study			

NEEDS	Scoring		Remarks
	A	B	
(b) To play			
(c) To socialize to spend time with others			
(d) Any other			
9. Because of having a sibling with mental retardation, do you need help in planning for your future ?			
10. Do you need help so that your parents spend time with all children equally?			
11. Do you need help so that your parents have normal expectations about your achievements ?			
12. Do you need help in managing family problems related to : (a) Your Spouse			
(b) Between your parents			
(c) Between parents and siblings with mental retardation			
(d) Between siblings			
(e) With other significant family members			
13. Do you need information on how to cheer up your parents when they feel sad ?			
14. Do you need information on how to make the community aware and accept persons with mental retardation ?			
15. Do you need information on various government benefits for your sibling and the family ?			
NIMH-FAMNS(Siblings) TOTAL SCORE			

NIMH-FAMNS(Siblings)

GOALS FOR INTERVENTION WITH SIBLINGS

Child's Name Date:

Sibling's Name :

Relationship with child : Brother/ Sister :

GOALS :

NIMH FAMILY NEEDS SCHEDULE (Grandparents)
NIMH-FAMNS(Grandparents)

RESPONDENT CHARACTERISTICS DATE : _____

Name:

Relationship with the index child : Grandmother/Grandfather

Age: Education: Occupation:

Address for correspondence :

Scoring : ENTER 2 IF NEED IS "**VERY MUCH**" A PRE-INTERVENTION SCORES
ENTER 1 IF NEED IS "**LITTLE**" B POST-INTERVENTION SCORES
ENTER 0 IF NEED IS "**NO NEED**"

NEEDS	Scoring		Remarks
	A	B	
1. Do you need information about your grandchild's condition or disability ?			
2. Do you need information on what your grandchild will be able to do/ and will not be able to do ?			
3. Do you need information on the services that are presently available for your grandchild ?			
4. Do you need information on how to manage/train your grandchild in : (a) Language and communication			
(b) Skill training			
(c) Problem behaviours management			
(d) Vocational training			
(e) Any other (Specify)			
5. Do you need information in how to involve yourself in meeting the needs of the the family ?			
6. Do you need help when you are worried, feel sad or depressed?			
7. Do you need help so that your children spend more time with you ?			
8. Do you need a home helper to look after your grandchild ?			
9. Do you need more time to self ?			
10. Do you need financial help to pay for medical care, medicine, therapy, or other services to meet your grandchild's needs ?			
11. Do you need help in seeking cooperation from professionals for the habilitation of your grandchild ?			
12. Do you need help in managing family problems related to : (a) Your spouse			
(b) Between parents of mentally retarded child			
(c) Between the parents and child with mental retardation			
(d) Between siblings and child with mental retardation			

NEEDS	Scoring		Remarks
	A	B	
(e) Between mentally retarded child and significant other family members			
13. Do you need information on future planning for your (a) Grandchild with mental retardation			
(b) Parents of mentally retarded child			
(c) Non handicapped grandchildren in the family			
(d) Other significant members in the family			
14. Do you need help in deciding whether to admit or not to admit your grandchild in a hostel ?			
15. Do you need information on various government benefits for your grandchild and the family ?			
NIMH-FAMNS(Grandparents): TOTAL SCORE			

NIMH-FAMNS(Grandparents)

GOALS FOR INTERVENTION WITH GRANDPARENTS

Child's Name : Date:

Grandparent's Name :

Relationship with child : Grandmother/Grandfather/Maternal/Paternal

GOALS :

Need Based Family Intervention Model

To meet the family needs, the family systems perspective should always be kept in view (see chapter 1). The need based family intervention model presented is envisaged to provide (a) guidelines to the service providers who have limited experience in working with the families having mentally retarded individuals; and (b) guidelines to the organizers of services, to select competent personnel for delivery of quality services by matching the required competencies to conduct need based family intervention programmes.

For the benefit of the organizers of the services and the users the, **'Need Based Family Intervention Model'** is described under three categories.

1. Assessment and information gathering.
2. Need based interventions
3. Professional competencies (knowledge and skills)

The model lists the possible nature of assessments, interventions and professional competencies required to meet all the possible needs included in the each of 15 areas of NIMH-FAMNS (Parents). There are obvious overlaps in assessments, interventions and professional competencies which have been listed for each NIMH-FAMNS need area separately.This has been intentionally designed so, to provide flexibility for one or more professionals depending upon their competencies to choose to work with the families in identified need areas. The service provider would be required to:

(a) Assess the individual needs of the parents using NIMH-FAMNS (Parents).

(b) Target specific needs for intervention from given areas in consultation with the concerned parent.

(c) Check from the 'Need Based Family Intervention Model' the suitable assessments required to meet specific target needs in the given area and gather information.

(d) Select from the 'Need Based Family Intervention Model' the suitable interventions to meet specific needs in the given area and conduct the same.

(e) For quality service delivery, check for the needed competencies before conducting the family intervention programmes.

OVERVIEW OF NEED BASED FAMILY INTERVENTION MODEL

NIMH-FAMNS - AREA I : INFORMATION-CONDITION

ASSESSMENT AND INFORMATION GATHERING	NEED BASED INTERVENTIONS	PROFESSIONAL COMPETENCIES (KNOWLEDGE AND SKILLS)
• Case history taking	• Communicating diagnosis, results of assessments and prognosis of index child	• Knowledge on mental retardation condition and differential diagnosis
• Medical assessment of the index child*	• Counselling parents and significant others and handling emotional reactions	• Knowledge and skills in medical assessment and interpretation of medical assessment reports
• Psychological assessment of the index child (intellectual, skills and problem behaviours)	• Facilitating contact with other parents having children with similar condition	• Knowledge and skills in psychological assessment and interpretation of psychological test results
	• Providing reading/audio/visual material for information and awareness building	• Knowledge and skills in counselling
	• Referral to needful services or further investigations	• Information on available services
		• Information on parent to parent support groups

* Index child here refers to the index person with mental retardation.

NIMH-FAMNS - AREA II : CHILD MANAGEMENT

ASSESSMENT AND INFORMATION GATHERING	NEED BASED INTERVENTIONS	PROFESSIONAL COMPETENCIES (KNOWLEDGE AND SKILLS)
• Behavioural profile of index child's skills and problem behaviours	• Parental/family counselling to help meet family needs	• Knowledge on the condition of mental retardation and life cycle needs
• Assessment of interaction patterns between parent-child, child-siblings, significant other members in the family and with significant neighbours, friends	• Behaviour modification programs for index child both for functional skills training and problem behaviour management	• Knowledge about child development
• Family functioning (family characteristics, needs, supports, coping and concerns)	• Providing information and conduct of special education programs with index child	• Knowledge about child rearing practices
• Ongoing training programmes if any being attended by the index child and related issues	• Facilitating parent-teacher contact and relationship	• Knowledge and skills about application of behaviour modification technology with the mentally retarded individuals
	• Conduct of need based parent training programmes on child management	• Knowledge and skills to conduct special education programmes
	• Facilitating parent participation in parent support groups involving siblings and grandparents	• Knowledge and skills to assess family functioning
	• Making available need based reading/ audio-visual material	• Knowledge and skills to facilitate parent to parent support groups
		• Information on available reading/audio-visual material

NIMH-FAMNS - AREA III : FACILITATING INTERACTION

ASSESSMENT AND INFORMATION GATHERING	NEED BASED INTERVENTIONS	PROFESSIONAL COMPETENCIES (KNOWLEDGE AND SKILLS)
• Behavioural profile of index child's skills and problem behaviours	• Communicating index child's assets and deficits	• Knowledge on the condition of mental retardation and life cycle needs
• Assessment of interaction patterns between parent-child, child-siblings, significant other members in the family and with significant neighbours, friends	• Parent and family counselling (handling emotional reactions, management of misconceptions, unrealistic expectations and unhealthy attitudes, helping redefine roles of family members)	• Knowledge and skills to conduct behavioural assessment of the index child
• Family functioning (family characteristics, needs, supports, coping and concerns)	• Imparting skills to communicate index child's condition to others	• Knowledge and skills to assess family functioning
• Neighbourhood environment	• Conducting need based intervention programs in the neighbourhood to facilitate healthy interactions	• Knowledge and skills to assess neighbourhood environment
	• Facilitating contact with parent to parent support groups	• Knowledge and skills in individual/ group counselling and psychotherapy
		• Knowledge and skills to conduct community awareness programmes
		• Knowledge and skills to facilitate parent to parent support groups

NIMH-FAMNS - AREA IV : SERVICES

ASSESSMENT AND INFORMATION GATHERING	NEED BASED INTERVENTIONS	PROFESSIONAL COMPETENCIES (KNOWLEDGE AND SKILLS)
• Behavioural profile of index child's skills and problem behaviours	• Communicating index child's present level of functioning and future life cycle needs	• Knowledge on the condition of mental retardation and life cycle needs
• Assessment of parental attitudes, misconceptions and expectations about the index child	• Counselling on the relative suitability of different models of training the index child, handling misconceptions, emotional reactions if any, related to special and integrated set-ups and helping parents to make appropriate decisions on schooling	• Knowledge and skills to conduct behavioural assessment of the index child
• Assessment of parental conceptions and attitudes towards different models of schooling for index child	• Providing information on availability of services suited to index child's needs	• Knowledge and skills related to psycho-educational assessment and special education training
	• Providing information and guidance on procuring training material and making suitable teaching aids to meet index child's needs	• Information on availablity of services/itinerant teachers and their relative effectiveness
		• Knowledge and skills in counselling

NIMH-FAMNS - AREA V : VOCATIONAL PLANNING

ASSESSMENT AND INFORMATION GATHERING	NEED BASED INTERVENTIONS	PROFESSIONAL COMPETENCIES (KNOWLEDGE AND SKILLS)
• Assessment of the index individual for vocational planning, training and placement	• Imparting information on assessment results related to index individual	• Knowledge on the condition of mental retardation and life cycle needs
• Family functioning (family characteristics, needs, supports, coping and concerns)	• Counselling parents, significant others and the index individual to help make right decisions for vocational planning, training and job placement	• Knowledge and skills to assess work related behaviours and job related skills
	• Field survey to identify job placement opportunities	• Knowledge and skills to assess family functioning
	• Assessment of the job situation	• Knowledge and skills to conduct vocational training programme which includes; field survey, job identification, job analysis and training
	• Job analysis	• Communication and social skills to interact effectively with people in the community, employers and colleagues of the index individual
	• Preparation of the index individual for the field of work in work behaviour and job related skills	• Knowledge and skills in vocational counselling and counselling the index individual and the family
	• Job placement and facilitating maintenance of job	

NIMH-FAMNS - AREA VI : SEXUALITY

ASSESSMENT AND INFORMATION GATHERING	NEED BASED INTERVENTIONS	PROFESSIONAL COMPETENCIES (KNOWLEDGE AND SKILLS)
• Medical assessment of the index individual's sexual characteristics and behaviour	• Counselling parents to handle their emotional reactions, family attitudes, providing information on sexuality issues to parents/significant others and to index individual	• Knowledge on the condition of mental retardation and life cycle needs
• Behavioural profile of index individual's skills and problem behaviours	• Medical treatment	• Knowledge of psycho-sexual development and sexual behaviours
• Parental attitudes towards sexuality and concerns related to index individual	• Behaviour modification of sexually abberant behaviours and adaptive skills building	• Knowledge and skills for medical examination and treatment
• Physical environment of the home, interactional patterns with in the family and immediate environment of the index individual	• Providing sex education to index individual	• Knowledge and skills for behavioural assessment of skills and problem behaviours
		• Knowledge and skills in counselling
		• Knowledge and skills to conduct sex education and behaviour modification programmes

NIMH-FAMNS - AREA VII: MARRIAGE

ASSESSMENT AND INFORMATION GATHERING	NEED BASED INTERVENTIONS	PROFESSIONAL COMPETENCIES (KNOWLEDGE AND SKILLS)
• Medical assessment of the index individual	• Medical intervention and genetic counselling	• Knowledge on the condition of mental retardation and life cycle needs
• Behavioural profile of the index child's skills and problem behaviours	• Counselling parents and significant others handling emotional reactions, providing information, correcting misconceptions on marriage issues related to index individual	• Knowledge on psycho-sexual development and sex education
• Parental/significant others perceptions, attitudes, expectations towards marriage issues related to index individual	• Providing sex education to the index individual	• Knowledge and skills for medical examination, treatment and genetic counselling
• Parental and significant others reported problems and concerns related to marriage issues of the index individual	• Training the index individual in adaptive skills for appropriate expression and fulfillment of sexual needs and skills for meeting marriage related responsibilities	• Knowledge and skills for behavioural assessment of skills and problem behaviours
• Assessment of the index family* characteristics, functioning, supports and expected marital roles	• Knowledge and skills to conduct Behaviour modification programs and sex education training of index individual	• Knowledge and skills in counselling index individual, family members and significant others
	• Facilitating contact with parent to parent support groups	• Knowledge and skills to facilitate parent to parent support groups

* Index family refers to family having mentally retarded individual

NIMH-FAMNS - AREA VIII : HOSTEL

ASSESSMENT AND INFORMATION GATHERING	NEED BASED INTERVENTIONS	PROFESSIONAL COMPETENCIES (KNOWLEDGE AND SKILLS)
• Behavioural profile of the index child's skills and problem behaviours	• Counselling parents and significant others on identified misconceptions, unhealthy attitudes, unrealistic expectations and social security issues related to index individual	• Knowledge on the condition of mental retardation and life cycle needs
• Family functioning (family characteristics, needs, supports, coping and concerns)	• Counselling parents and significant others in handling the emotional reactions and building natural support systems	• Knowledge and skills in behavioural assessment of skills and problem behaviours
• Perceptions, expectations, attitudes of parents and significant others related to index individual	• Counselling parents and significant members on merits/demerits of hostel placement, and facilitating decision making	• Knowledge and skills to assess family functioning
• Possible reasons for hostel placement	• Facilitating contact with parent to parent support groups	• Knowledge and skills in counselling
	• Providing information on available hostel facilities	• Information on list of hostel facilities in the country
		• Knowledge and skills to initiate and facilitate parent to parent support groups

NIMH-FAMNS - AREA IX : PERSONAL - EMOTIONAL

ASSESSMENT AND INFORMATION GATHERING	NEED BASED INTERVENTIONS	PROFESSIONAL COMPETENCIES (KNOWLEDGE AND SKILLS)
• Medical assessment of the index parent*	• Medical intervention	• Knowledge on the condition of mental retardation and life cycle needs
• Psychological assessment and mental status examination of the index parent	• Individual counselling psycho-therapy with index parent for healthy adaptation	• Knowledge and skills in medical assessment and treatment
• Family functioning (family characteristics, needs, supports, coping and concerns)	• Train index parent in time management skills	• Knowledge and skills to conduct psychological assessment and mental status examination
• Behavioural profile of index child's skills and problem behaviours	• Counselling with different members of the family making them aware of individual needs of each member working towards total family involvement redefining roles and sharing responsibilities	• Knowledge and skills to assess family functioning
• Profile of daily schedule routine of activities of the index parent and other family members	• Help build supports for index parent	• Knowledge and skills in Behavioural assessment of skills and problem behaviours
	• Provide information on parent support groups and facilitate parent participation	• Knowledge and skills in counselling parents and significant others
		• Knowledge and skills in psycho-therapy
		• Information on existing parent to parent support groups
		• Knowledge and skills to initiate and facilitate parent to parent support groups

* Index parent here refers to the parent of the mentally retarded individual

NIMH-FAMNS - AREA X - PERSONAL-SOCIAL

ASSESSMENT AND INFORMATION GATHERING	NEED BASED INTERVENTIONS	PROFESSIONAL COMPETENCIES (KNOWLEDGE AND SKILLS)
• Behavioural profile of index child's skills and problem behaviours	• Individual counselling/psycho therapy with the index parent for healthy adaptation	• Knowledge on the condition of mental retardation and life cycle needs
• Family functioning (family characteristics, needs, supports, coping and concerns)	• Counselling with different members of the family, making them aware of needs of each member	• Knowledge and skills to assess family functioning
• Assessment of index parent knowledge about index child's condition, attitudes and expectations	• Help build supports for index parent	• Knowledge and skills in behavioural assessment of skills and problem behaviours
	• Provide information on parent to parent support groups and facilitate parent participation	• Knowledge and skills in counselling parents and significant others
		• Knowledge and skills in psycho-therapy
		• Information on existing parent to parent support groups
		• Knowledge and skills to initiate and facilitate parent support groups

NIMH-FAMNS - AREA XI : SUPPORT - PHYSICAL

ASSESSMENT AND INFORMATION GATHERING	NEED BASED INTERVENTIONS	PROFESSIONAL COMPETENCIES (KNOWLEDGE AND SKILLS)
• Behavioural profile of index child's skills and problem behaviours	• Individual/family counselling to facilitate appropriate solutions to existing problems/concerns	• Knowledge on the condition of mental retardation and life cycle needs
• Family functioning (family characteristics, needs, supports, coping and concerns)	• Building formal and informal supports to meet the identified needs	• Knowledge and skills in Behavioural assessment of skills and problem behaviours
	• Providing information on available resources on transport escorts and home helpers	• Communication, social interaction and management skills to organise volunteers for mobilizing physical support for families
	• Training of individuals providing physical support services	• Knowledge and skills to conduct training programmes for volunteers/helpers
	• Facilitating contact with parent to parent support groups	• Knowledge and skills to initiate and facilitate parent to parent support groups

NIMH-FAMNS - AREA XII : FINANCIAL

ASSESSMENT AND INFORMATION GATHERING	NEED BASED INTERVENTIONS	PROFESSIONAL COMPETENCIES (KNOWLEDGE AND SKILLS)
• Medical assessment	• Individual/family counselling to identify sources to raise family income to meet expenditures on long term basis	• Knowledge on the condition of mental retardation and life cycle needs
		• Knowledge and skills in medical assessment
• Psychological assessment of the index child (intellectual and behavioural assessment of skills and problem behaviours)	• Providing needful help to avail government benefits and concessions	• Knowledge and skills in psychological assessment
	• Providing information to parents on evitable equipment and materials for meeting training needs.	• Communication skills, social interaction skills and management skills to mobilise financial resources for families
• Identifying index child's related needs requiring financial support	• Identifying, meeting and mobilizing volunteers and voluntary organisations to meet the financial needs of the families	• Knowledge and skills to identify suitable training/material needs of index child requiring financial support
• Assessment of financial status of the family and sources of income	• Facilitating contact between the needy families and the voluntary financial supporters	• Information on available government benefits and concessions to families having individuals with disabilities
		• Information list of volunteers/voluntary organisations prepared to provide financial support
		• Monitoring the utilisation of the financial support provided to index child

NIMH-FAMNS - AREA XIII : FAMILY RELATIONSHIPS

ASSESSMENT AND INFORMATION GATHERING	NEED BASED INTERVENTIONS	PROFESSIONAL COMPETENCIES (KNOWLEDGE AND SKILLS)
• Behavioural profile of index child's skills and problem behaviours	• Providing information on index child's condition to parents, siblings and other family members	• Knowledge on the condition of mental retardation and life cycle needs
• Family functioning (family characteristics, needs, supports, coping and concerns)	• Counselling management of misconceptions and unhealthy attitudes of parents, siblings or other significant family members	• Knowledge and skills to assess family functioning
• Interactional patterns between parents, index child and significant members of the family	• Counselling/psycho-therapy to meet identified needs of different members of the family	• Knowledge and skills in the behavioural assessment of skills and problem behaviours
• Parental, siblings perceptions and attitudes towards the index child	• Facilitating participation of parents and significant other members in parent to parent support groups	• Knowledge and skills in counselling Knowledge and skills in psycho-therapy
		• Knowledge on existing parent/family support groups
		• Knowledge and skills to initiate and facilitate parent to parent support groups

NIMH-FAMNS - AREA XIV - FUTURE PLANNING

ASSESSMENT AND INFORMATION GATHERING	NEED BASED INTERVENTIONS	PROFESSIONAL COMPETENCIES (KNOWLEDGE AND SKILLS)
• Psychological assessment (intellectual and behavioural assessment of skills and problem behaviours of index child)	• Helping parents understand assets and limitations of the index child	• Knowledge on the condition of mental retardation and life cycle needs
• Family functioning (family characteristics, needs, coping, supports and concern)	• Counselling parents and other significant members of the family related to financial planning and social security to help make appropriate decisions	• Knowledge and skills in Psychological assessment
• Parental and family concerns related to financial planning for the index child's training	• Helping build informal/formal social security supports for index child	• Knowledge of financial and social security schemes
• Parental and family concerns related to future planning for the index child's social security	• Facilitating transfer of pension and other assets to the index child	• Knowledge related to legal aspects in transfering assets to index individual
• Family assets which parents would like to transfer on to the index child	• Facilitating contact with parent to parent support groups	• Knowledge and skills in counselling
		• Information on existing parent to parent support groups
		• Knowledge and skills to initiate parent to parent support groups

NIMH-FAMNS - AREA XV - GOVERNMENT BENEFITS AND LEGISLATION

ASSESSMENT AND INFORMATION GATHERING	NEED BASED INTERVENTIONS	PROFESSIONAL COMPETENCIES (KNOWLEDGE AND SKILLS)
• Psychological assessment (Intellectual and behavioural assessment of skills and problem behaviours of index child)	• Providing information on Government benefits and concessions available to mentally retarded child and the family	• Knowledge on the condition of mental retardation and life cycle needs
• Family functioning (family characteristics, needs, supports, coping and concerns)	• Help parents avail Government benefits and concessions as per eligibility	• Knowledge about available Government policies, Government benefits and concessions to mentally retarded individuals and their families
• Information on concerns of parents and significant others	• Providing information on legislation related to mentally retarded individuals	• Knowledge about legislation for the mentally retarded individuals

CONCLUSION

The empirical understanding on the **impact, needs, supports and coping** of families having mentally retarded individuals presented in the preceding chapters, development of **NIMH-Family Needs Schedule and Need Based Family Intervention Model** are just a beginning in the much required further work that needs to be done towards strengthening Indian families having mentally retarded individuals.

REFERENCES

Dunst, C.J. & Leet, H.E. (1987). **Measuring the adequacy of resources in households with young children.** Child Care. Health and Development, 13, 111-125.

Dunst, C.J., Leet, H.E., Vance, S.D., & Cooper, C.S. (1986). **Resource scale for teenage mothers.** Unpublished scale, family, Infant and Preschool Program, Western Carolina Centre, Morganton, NC.

Dunst, C.J., & Trivette, C.M. (1985a). **Support function scale: Reliability and validity.** Unpublished scale, Family, Infant and Preschool Program. Western Carolina Center. Morganton, NC.

Dunst, C.J., Vance, S.D., & Cooper, C.S. (1986). **A Social systems perspective of adolescent pregnancy: Determinants of parent and parent-child behaviour.** Infant Mental Health Journal, 7, 34-48.

Everybody thinks of changing humanity and nobody thinks of changing himself

Leo Tolstoy

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For the last 20 years she has been actively involved in the treatment of emotional and behaviour problems in children and working with the families. So far she has conducted nearly 80 training workshops across the country for parents and professionals working in the field of mental handicap in the application of behaviourally based methods for teaching and training of children with severe learning difficulties, psychological and behavioural assessment, working with families and counselling skills.

She has contributed nearly 20 research papers in reputed national and international journals. She has written chapters for books, and also published books as first author which includes "Managing Behaviour Problems in Children: A Guide for Parents" (1990); "Play Activities for Young children with Special Needs" (1991); Behavioural Approach in Teaching Mentally Retarded Children: A manual for Teachers" (1992); "Moving Forward - an information guide for parents of children with mental retardation" (1994). She has also co-authored training manuals "Mental Handicap: A manual for Psychologists" (1988): and "Mental Handicap - A manual for Guidance and Counsellors" (1989). Besides that she has also produced a 30 minutes video film titled "*Manzil*

Ke Ore" for meeting the information needs of parents having mentally handicapped children.

DESH KEERTI MENON is the Director of the National Institute for the Mentally Handicapped, Secunderabad since its inception in the year 1984. After his post graduate degree in Psychology from Punjab University in the year 1968, he underwent two years of training in Clinical Psychology at the Central Institute of Psychiatry, Ranchi where he passed his DM&SP with distinction in the year 1971. He obtained his Ph.D. in Clinical Psychology from Post Graduate Institute of Education and Research in the year 1980. He has worked in various capacities as a District Guidance Counsellor in Chandigarh; Clinical Psychologist at Punjab Mental Hospital, Amritsar; Senior Social Scientist with World Health Organization Collaborating Centre at Post Graduate Institute, Chandigarh; Senior Research Officer with Indian Council of Medical Research, New Delhi before taking up the Director's position at NIMH.

Over the last 25 years, he has contributed significantly in the field of mental retardation and mental health. He is on various national level policy planning committees which includes Advisory Committee on Mental Health, Indian Council of Medical Research; working Group on Handicapped, Planning Commission; National Council on Welfare of the Handicapped, Ministry of Welfare, Govt. of India; Rehabilitation Council's Committee on mental retardation; and Coordination Committee for the education and welfare of the handicapped, Ministry of Human Resource Development.

He has nearly 50 publications to his credit which have been published in reputed national and international journals. Which includes books, chapters in books and research papers. His publications have been mainly in the areas of early intervention, families, vocational rehabilitation, community awareness and materials for rural health workers.

RAHUL GANGULY was the Research Officer in the multi centered "Strengthening Families Project" funded by National Institute for the Mentally Handicapped (NIMH) Secunderabad. Presently, he is working as the Training Coordinator and Consultant in developmental disabilities at Training and Research Centre in Rehabilitation, Arogyavaram, Andhra Pradesh. He obtained his Bachelor's degree in mental Retardation from the National Institute for the Mentally Handicapped in 1990. On receiving Graduate

Teaching Fellowship award from Specialised Training Centre, University of Oregon (USA), he underwent two years of intensive training program leading to Master of Science (Special Education and Rehabilitation).Following post graduation in 1992, he has worked as a Systems Change Consultant for Washington County Mental Health, Vermont (USA). In addition, he has also worked as Employment Training Specialist with Mckenzie Personnel Systems (Oregon, USA) and has been associated with federally funded Employment Projects, at University of Oregon for nearly two years.

Over the past 4 years, he has actively involved in the training and rehabilitation of the individuals with severe disabilities. His work has focused on supporting families achieve desirable lifestlyes for their son/daughter with mental retardation and also assisting human service agencies to be more responsive to family and individuals need. His areas of interest include working with families of individuals with autism and computer assisted vocational rehabilitation of individuals with mental retardation.

SUMIT ROY is the Executive Director of Digdarshika Institute of Research and Rehabilitation, Bhopal which he established in 1990 along with his wife Smt. Kakoli Roy (Also a clinical psychologist). He is the Coordinator of the Diploma course in Mental Retardation at Digdarshika. After obtaining his postgraduate degree in Applied Psychology in the year 1982, he underwent two years training in Clinical psychology at Central Institute of Psychiatry, Ranchi, where he passed DM&SP in 1984. He has worked at Christian Missionary Hospital in Bethul District (M.P.) as a clinical psychologist. In addition, he has also worked as Research Officer at the All India Institute of Medical Sciences, New Delhi and at Indian Council of Medical Research project for Bhopal Gas Tragedy Victims.

Over the past 10 years he has been actively involved in the asessment, diagnosis and treatment/training of individuals with psychological problems, disabilities and impairements. In addition, he has conducted workshops for families and the community as part of community mental health programmes. He has published research papers in reputed journals and written articles for newspapers in the field of mental health. His areas of interest include working with families of children with mental retardation having psychological problems and awareness building in the community.

RAJAM P.R.S. PILLAY is the Director of Balavikas Training Centre, Trivandrum and also the coordinator of Diploma Course in Mental Retardation at the Balavikas Training Centre. After obtaining her postgraduate degree in History from University of Bombay in the year 1962, she completed her Master degree in Education (Ed.M) from Boston University (USA) in the year 1970. She also completed her Ph.D in the year 1994 from Kerala University. She has been the executive secretary of Federation for the Welfare of the Mentally Retarded in New Delhi. Presently, she is the member of the High Level Committee constituted by the Kerala Government for drafting curriculum for teaching children with mental retardation. She is also a member of the curriculum committee, NIMH and a member of the Advisory Committee on Mental Retardation, Rehabilitation Council of India.

She is keenly involved in promoting human resource development in the field of rehabilitation in the state of Kerala. For the last four years she has been conducting state level seminars annually in Kerala on mental disability. She has published over 30 articles on various aspects of mental retardation besides giving series of radio talks on mental retardation on All India Radio.

ASHA GUPTA is presently working as Principal/Director Navjyoti Centre for Children with Special Needs. After obtaining her Bachelor's degree in 1964 she underwent one year of training leading to Diploma in Child Education (University of Delhi) in 1970. She also completed a certificate course in Special Education offered by the Federation for the Welfare of Mentally Retarded in 1982 and completed one year diploma course in mental retardation from Regional Training Centre of National Institute for the Mentally Handicapped, New Delhi in 1987. She has worked as a teacher in Balwant Rai Mehta School for Exceptional Children in New Delhi for nearly two years.

Over the last 14 years she has been involved in the training of individuals with mental retardation. She is a parent of a son with mental retardation. She has established Navjyoti Centre to provide individuals with mental retardation maximum opportunities for participating in occupations of their choice. Presently, her area of interest lies in developing strategies for the economic rehabilitation of the individuals with mental retardation. She is also a member of Samadhan Association (New Delhi) and treasurer of the Marketing Federation for the Handicapped (New Delhi).