

SWIMMING TOGETHER - A SPLENDID EXPERIENCE

(A Pragmatic Parent-Professional Attempt)

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This paper throws light on the invisible inner feelings of most of the parents, especially mothers of the mentally handicapped, that are normally hidden and not expressed, for fear of getting break-ups in the on-going family relations and constraints in the continued-marital tie ups.

India's Social Structure is different from that of other advanced countries. Ancient India carries a great traditional treasure consisting of invaluable cultural heritage. Most of the Indian families prefer to live under the control of one family head, honoring the traditionally structured family system. Principle of obedience play a greater role and family members are abide to certain verbal and unwritten rules by habitual practice. They love to follow simply what parents say (sons) and daughters in-law are expected to follow what their husband says. The in-laws act as custodians and administer the family affairs. This time-honored practice is imbibed in the Indian culture and this tradition is being transmitted from generation to generation.

The strong convictions and unchanged attitude of the elderly started bringing plenty of problems in due course of time causing confusion and greater misunderstanding in the day to day family affairs. Non-attention or negative expression of the daughters-in-law to in-laws result in splits in the family and even to separation of wife and husband.

Families having a kid with mental retardation is not an exception from this situation. This blind-belief traditional practice started hitting the confidence of the parents greatly, especially mothers, creating plenty of parent-related problems, such as worry, tension, fear, disappointment, feeling of insecurity etc that encircle the whole family. If these problems are neglected and not given proper attention they may turn into major family-centered issues and affect the whole family breaking into pieces.

It is evident that difficulties do not arise from external environment. They spring out only from the structured- goals and un-matching demands of either the in-laws or sometimes the parents themselves. Mothers that are caught in the conventional and traditional family framework become tongue-tied and greatly inept as their lives are more threatened and questioned for security. Such mothers must be brought out of the age-old structured-family-system that keeps them under the firm fist of meddling mother in-law.

This requires brimming confidence in such mothers to help them realize their inner power and to know their parental responsibilities properly. A sense of awareness creation and understanding promotion is highly essential.

For this purpose several Symposiums and various workshops were organized at Lebenshilfe to answer the questions raised by parents, to address their concerns and also to help them advocate the causes ,voicing their opinions.

A Symposium to open mind and give hope

A symposium was organized at Lebenshilfe with the title' Swimming Together –A Splendid Experience helped the parents to address their concerns, to voice their opinions, to advocate their problems to establish good networking with the other parents.

Parents from different walks of life attended with much enthusiasm and more interest and discussed thoroughly on diversified problems causing a deep sense of sorrow, confusion, fear, anxiety, and worry about the future of their M.R. Kids. Pleasantries exchanged and the fun and frolic activities participate by them stand significant.

Parents had a platform to ventilate their displeasures, negative thoughts and guilty feelings.

This Symposium left heart-warming stories, stirring experiences, touching episodes that captured even the heart-beat sometimes. As parents wanted to keep up privacy, this paper can not share all of them with the delegates.

Some mothers were so open to tell how their spouses use anger, pout, shouting, threatening to make things much more difficult to please their parents and other family members blaming her alone for the birth of the retarded child.

Parents were bonded in a unique way which provided a 'spectacle' to the on-lookers in the campus. They are united strongly by the sorrowful situations because of the mentally handicapped child.

The outcome of the Symposium in which 60 parents worked in 15 groups with 50 staff members, was to permit right thoughts can show the parents a right path leading to a sense of total relaxation. Moral courage filled in their minds drives them to understand the situation and confidence helps them to choose right activities which wash out the anxiety, stress, and disappointment

Parents agree:

Parents are responsible to take their retarded children either to heights or further down to earth.

They should observe the psychological insights, strengths and weaknesses, inconsistencies etc... while dealing with their retarded children.

Organizing individual counseling, open discussion sessions, involvement in various collaboration-promotion activities and establishing a healthy networking with other parents facing the same problems made a lot of difference.

This paper furnishes certain evident-based information from the recent symposium cum workshop organized at Lebenshilfe with.

Why to organize a Workshop and what happened in?

Through the process of communication ideas were transmitted from one mind to other and from one mother to another, intentionally directed by the internal chaos undergoing. This exchange of communications and feelings was useful to overcome several family-based problems: parents were able to swim together with other parents against the sea of difficulties to obtain best results and live better.

What do mothers expect?

From husband:

Going out, do shopping, eating elsewhere, sharing pains and pleasures, seeing a movie together, love and affection etc.

Attending the social functions with the same human dignity.

From home:

Human respect from family members.

Sleep well during the night times without getting disturbed.

**Having a tension free and stainless atmosphere.
Relief from meddle ling mother in-laws.**

From Society:

**Attending the social functions with the same human dignity.
Good social relations and better networking with other parents.**

For their Children:

**A secured future causing happiness to the entire family after them.
An independent life without depending on others.**

What do fathers expect?

**A pleasant atmosphere where no disturbance is seen.
Wife's Personal attention and inter-personal love only to him.
Respect to their parents, and other family members from his wife.
Holding total responsibility of the M.R. Child besides entire family care.
Wife staying at home with M.R. Child while he attends out-side visitations.
Going out for sometime seeking relief from the household pressures.
Keeping away from home for external relaxation.**

Both of them actively participated in the Workshop to recognize self-defeating problems and to share their experiences arising out of them.

They accepted that life is nothing but a journey starting from birth going towards death. It is a combination of pains and pleasures. They travel with us as co-passengers all throughout our life which we can not avoid them. We have to accept them and continue our travel till we reach our destination.

It deals with the parent-related issues through counseling, interaction and collaboration, stimulating the parental curiosity over the problems encircling their families and how certain situations seriously hit the inner confidence of the parents, especially mothers.

It helps the parents find out various reasons causing disturbance to their peaceful living and make them realize the importance of bringing a balance between their actions and the expected values of the other family members. It also emphasizes on suitable solutions for overcoming the problems

Parents wish to see their children participating fully and actively in the contemporary society.

Most of the times in a few cases and sometimes in most of the cases, parents at home and teachers at school terribly fail to stimulate the severely retarded kids which causes deviation from normal behavior. Often I undergo tension in the day to day running of home.

Husbands think that mother is the primary respondent to family's needs and hence she should bear the entire burden including the burden of the M.R. Child.

“I face struggle in my own family. My parents and in-laws do not accept that my child is a retarded child. He looks normal and hence they think he is normal. They expect the same behaviour of the similar aged children and failure makes them get annoyed. I am compelled to beat him many times to satisfy the elders. The home atmosphere is much stressful to me.”

“If we don’t agree with a person, we can just walk away but we can not walk away from a mentally handicapped kid. It may be possible to some delighted Dads likes to get rid of the burden but not to the mothers in melancholy. Family’s distrust and my husband mistrust hit my confidence so seriously.”

“Despite receiving deliberate insults, still I am alive because of the moral strength given by Lebenshilfe. My feelings are deeply hurt when my own in-laws abused me targeting my character when I started bringing my son to Lebenshilfe for training much against their will.”

It also suggests suitable ways to parents to study their family situations carefully from psychological, Social and medical aspects and help them come out of such situations brimming confidence in the parents.

Santosh learned to find his calm

Mother of Santosh says her son was quite normal till he was four and since then change in behavior was seen. He has a sister, studying Engineering and the age difference between the two is only two years.

At home neither the father nor the other family members speak with him. As a result he embraces forceful isolation, He is kept in a room-locked and not allowed to come out. She tries to emphasize the need for placing him among others for promotion of friendly and social relations that helps him reduce certain severe behavior problems but nobody cares her and she says ‘ she is helpless’.

My plans to send him out for sometime also bring greater problems. All my neighbors are higher officials. They decorate their homes with expensive items and imported materials. They do not allow him to visit their homes as he breaks and destroys things when he goes out of control in anger. I have major problems when the school is closed for holidays. He likes the school and he wants to attend the school no matter whether it is opened or closed. Lebenshilfe knows his pulse to keep his emotions always under control. He gets annoyed seeing his father and other family members as they do not give any human respect to him. Human respect is not shown in interpersonal relationships and hence the situation. I appreciate summer-schooling to this boy.

A variety of activities was suggested connected with interactive learning experiences such as reading, singing, playing, and talking about what he sees and what he does

Supply of missing love, Extending human respect and dignity. Free movement with the family members. Bringing him out of isolation, Make him talk with the neighbors etc. Need for a proper rapport development.

Conclusion

A clean sense of purpose, a global vision, a sense of understanding over the problems and prevailing possibilities, Realization of resources, awareness of needs

Moral courage to take up the task against the will of the parents

Life is a combination of pains and pleasures. It is a journey from birth to death. Pains and pleasures are the co-passengers that we can not avoid them.

Parents realized that they have a common interest and complimentary responsibility from promoting security, stability and prosperity of all the children growing with their growing age.

My participation bringing a bunch of ideas from a developing country like India would be a biggest honor to add a bit to the global ideas for which this conference is being organized.

Smiles were exchanged to generate trust and confidence. The positive attitude of the parents spread cheers at the end of the Symposium.

They came weak and went back with a greater strength.

They brought countless thoughts and shared considerable experiences.

Most of the family members expect a dramatic change in their retarded children which brings disappointment. They came with a common motto respected each other and appreciated each other's problems. They opened themselves sharing their grief.

Exchanged experiences seeking solutions, solutions that give a sense of relief

Many parents live with strained relations blaming each other and become tongue-tied and terribly inept.

Most of the mothers show endless patience. No mother likes to see her child cry.

Men and women are different in ventilating their displeasures.

Parental feelings of happiness begin to fade when they come to know that their children are different in behaviour.

Men and women are different in ventilating their displeasures.

Disability does not arise from individuals. It springs from the failure of the families.

Difficulties do not arise from the external environment. It springs from the failure of the family members to understand the problem and refuse to seek solutions.

Kids with mental retardation have an equal right to grow up in a healthy, safe, comfortable and loving environment. Kids kept away from situations contrary to these conditions show anti-social behaviour causing severe behaviour problems for missing of love, affection, warmth and rejection from their own family resulting loneliness. Progress can be assessed and clearly monitored by the personal rapport developed between the M.R. Child and the parent at home and with the teacher or therapist at school.