

From Locked Homes to Secured Societies

History starting from yesteryears

A teenager's figment of imagination turns into reality resulting Lebenshilfe's existence

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INTRODUCTION

This chapter gives the synthesis of the entire work experience of the author for over three and half decades. In one way it is like a keynote of the article and will form a clear cut understanding of what motivated the author to bring Lebenshilfe into existence and how this organization is being driven towards its goal, pushing towards heights of achievements overcoming hardships and to reach its heights through various innovative therapies and need based activities etc. The author's Lifelong journey started from 1980 is being continued till to date receiving periodical help, assistance and advises of experts in the fields of Special Education, Departments of

Psychology and Education of Andhra University, from Dr Giuliana Galli Carminati at the time from the University Hospitals of Geneva, Dept. of UPDM, Switzerland and her team of Psychologists and from a number of experts who have been visiting Lebenshilfe from different universities, international organizations of the world, using the information and data gathered from consultations with reputed professors to the related field and the personal experiences of the author working with the mentally handicapped from children to adults. Also some information collected from international conferences, roundtables, workshops and symposia attended by the author personally while presenting papers further strengthened the author's endeavors. The author as a researcher has carefully tabulated this yielded enormous amount of data which she carefully embedded into this article to further strengthen the on-going work of Lebenshilfe serving the people having intellectual disabilities hailing from poorer sections of the society.

Lebenshilfe-India, the conception (1962-1980)

The author who has a natural flair for life developed herself to serve the mentally handicapped people. Added to this, she is blessed with an inborn eagerness to serve the mankind. She was born in a middle class family, which is a combination of modern and orthodox views. The father being a High

School Head Master was always sympathetic to the suffering humanity and her mother being an orthodox person always attributed suffering to the "KARMA" (human act) of previous birth. But since her father's influence is more on the author, she developed a very sympathetic view to the suffering humanity.

In her childhood the author had come across a few people having mental retardation in her native village, Vegeswarapuram, in her uncle's village KadakatlaThota, as well as in her relative's family at Bommidi village in West Godavari District of Andhra Pradesh etc. It was most heartening to see them tied up to the legs of a cot or to the window bars in a separate room, simply feeding them and wrapping in rags with periodical intervals. Yet times they were turning aggressive and unfortunately no one could not understand what causes that state of aggression and how to bring that situation under control. She always questioned herself during her childhood 'Why these people are born like that? Why they look different from others? Why are they locked in a separate room and being beaten up? Why were they kept under isolation? How to make them normal?' Such questions rocked her thoughts.

After completion of her High School Studies she was sent to a most reputed Catholic Institution namely St. Ann's Training School of St. Theresa's

Convent for Women at Eluru, W.G. District to receive teachers credentials (for a two-year study). She studied psychology with great interest during this training period. Certain incidents witnessed personally by the author at her age of 17 during her teen age and another incident that took place at her age of 32 after completion of her higher studies at USA impacted her greatly and these unpleasant incidents drove her to start Lebenshilfe in the year 1980 with a commitment to extend services free to the mentally handicapped children hailing from poorer sections of the society.

Those were the days , way back in 1962, the author was walking down the street to have her a 'Brunch' in a hotel located right in front of the Out Patient Gate of King George Hospital (KGH) Visakhapatnam. Her eye-balls stopped moving, eye-brows raised for a moment with surprise while seeing a begging lady with a mentally handicapped child in her arms, holding tightly, asking people passing by to give a bit of money to feed the baby. A few weeks later the author happened to see the same lady once again in the same place begging as usual, but this time, drinking a cup of tea standing in the hot sun and not caring the crying child. Upon enquiry she told that the baby was not hers and rented for the purpose of begging. When asked why she was drinking tea alone and not giving at least a bit of milk to the baby, her answer

was quite surprising. She said she bought the tea from her part of earning from begging. Half of the money from what little she got had to be given by evening to the mother of the child as she would not keep quiet if her share was reduced. That unfortunate child turned into a source for earning livelihood to someone, not known and carried no love for her.

The author decided that moment itself to do something for such people in future. Later she got an opportunity to join as a teacher at R.C.D. Hospital where she served the polio affected children and mentally handicapped children for 20 years. But her services were confined only to teaching rather than service. At that juncture she was selected for Rotary Foundation of Rotary International's 'TEACHERS FOR THE HANDICAPPED' award which helped her to study Special Education at Connecticut, USA.

Parental Feelings: Some spend even sleepless nights, no matter they are full moon or moonless nights. Taking the mentally retarded into the fold for training is a beginning with no ending. Training these people require a thoughtful planning with innovative ideas, creative-oriented and need-based activities suitable for their intellectual level of perception, reception, cognition and reciprocation. Similarly training the parents and families of these children caught in deep shock or sorrow, is equally important. Many carry no

meaningful thoughts about the failure of their ill-fated kids as most of them are illiterate Parents. They desperately look for some supporting hands. They are more worried and spend countless days to find a way out. They indeed need a helping hand followed by a sense of moral support. They need greater confidence to face the challenges that frighten them which follow one by one till their children stand on their legs in the society. It must be well-planned and carefully designed so that it suits their occupation. Most of the parents who are uneducated were scheduled carefully. While working with the mentally handicapped and their families, the author in those days was trying to collect their pleasures and displeasures, what exactly bothers them and what is that they expect and what help they require to come out of their situation?

It is a fact that " they are mentally handicapped and look different. Many think that they are of no use. It is because of lack of proper awareness . If trained properly they attain a life with dignity and quality proving that they are of great use. They can be transmitted into useful contributors of the society.

Importance of Home: The very idea of home and its impact on the families is different to different people. Once on a fine morning the author has come across another event which has turned down and thrown the entire family into

major difficulties throwing the grandma in a most pathetic and helpless situation and leaving the whole family burden on her feeble shoulders.

What was that event?

The author happened to see a 75 year old grand-ma and her 13 year old severely mentally handicapped grand-daughter in the premises of R.C.D. Hospital where she was working as an educational instructor for polio affected children. She found her unbearably carrying her grand child having severe retardation telling in a broken voice, "she is neither dead nor an used Sandal. Had I found her either the way, I could have thrown her here itself in the Bay of Bengal and gone back. Banging her head with her hands, she continued saying with tears pouring over her cheeks," I have nobody and no money. What should I do with this girl?. I can not take care of her. Who comes to my rescue at this age?" For a very long time these two incidents started influencing the author with a deep sense of understanding of the unbearable pain undergoing by the parents and families, helping her to understand the facts and realities of such situations.

Later the author had an opportunity to study Special Education concerning the handicapped at USA and to receive intensive in-service training in the field of Mental Retardation from Lebenshilfe, West Germany (1978-79).Immediately after

her return from Germany, she was invited to a well reputed service organization to share her experiences abroad.

.An Insult Turned Into A Challenge

Lebenshilfe came into existence as a non-profitable and non-governmental organization (NGO) of India to deal with problems connected with mental retardation. It was born from an insult received while addressing a service organization as its head-speaker. In the midst of more than 350 participants founder's desire to start a possibility for the mentally handicapped children like in Western and other European countries was expressed asking for moral support. One participant responded bluntly, saying there is no need to start such a school as there were not enough number of schools to educate the normal people. She was deeply hurt with his further comment, saying "may be she is carrying a lose nut for making such plans for mentally retarded who are of no use in any manner either to the society or to themselves." The entire hall was reverberated with laughter from the audience. She welcomed the challenging situation silently which helped her opening doors for further planning to translate her ardent desire into reality.

After a while, digesting the situation silently she has taken up a decision to start a center for mentally handicapped asking no help from anybody which resulted in today's Lebenshilfe, a pioneering institution engaged in extending service-free training to the retarded, moral strength to the parents and counseling to families in blues. It was Tom Mutters that supported her idea, acting as a God-father with initial financial assistance and necessary guidelines

to bring out Lebenshilfe, the Germany's National Organization with the same name and emblem in India in the year 1980.

This article attempts to give a brief description of Lebenshilfe Organization, the circumstances under which it was established, different therapies adopted by this institute to the students with different levels of aberrant behavior, participation of the author in various international conferences, symposia, workshops presenting papers and how this acquired knowledge enabled to take up a venture to start Lebenshilfe are to quote some.

Secret of Success: Nothing but implementation of A-Z activities consisting innovative and productive precisely. High happiness to Lebenshilfe quotient is slogan of successful organization. Happy people will be more innovative Service providers to be the source of happiness to parents and families, leading them to the fruitful lives of their children having mental retardation, driving them towards economic independence. It is undoubtedly a great venture, the motivation level being very high, making everyone content to a large extent.

Development of creative thinking skills: This is possible through innovation & activities for emotional intelligence promotion. Innovation helps to achieve required environment to reach a higher level of efficiency.

Years rolled by, It is now a score: Lebenshilfe founded in 1980 by the author Dr T.Saraswathi Devi (Sarah) started its initial classrooms organization in thatched huts & under the trees. Our source of strength and the outcomes achieved are stored in our hearts. The lessons we could learn carried cores of values that are instilled in the hearts of mothers who come forward to vent their feelings. Before planning for need-based and appropriate activities suitable for overall development of mentally handicapped, Lebenshilfe has conducted orientation classes to the Teaching staff in the area of importance of Education and need for Special Education.

What is Education and why we need Special Education?

Education is a powerful instrument of social change and often initiates upward movement in the social structures. It helps in bridging the gap between the different sections of the society. The educational scene in the country has undergone major changes over the years resulting better provision of education and better educational practices.

Education is one of the essential inputs to ensure the quality of an individual.

This is why the right to education finds a place in the constitution.

Special education is the education of students with special needs in a way that addresses the student's individual differences and needs. Ideally, this process involves the individually planned and systematically monitored arrangement of teaching procedures, adapted equipment and materials accessible settings and other interventions designed to help the learner with special needs, achieve a higher level of personal self-sufficiency and success in the school and community. Common special needs include challenges with learning communication challenges, emotional and behavioral disorders, physical disabilities and developmental disorders. Children with these kinds of special disorder are likely to develop from programs through training and functional educational services..

Lebenshilfe's Role

To make their lives more meaningful and manageable through considerable training starting from nursery to vocational, Lebenshilfe created need-based activities for the purpose and innovated therapies such as tiger dance therapy, art therapy music therapy, musical instruments play, Raga therapy, dance therapy, Snoezelen (Dutch Therapy) for sensorial stimulation , sand play, sports and traditional games, pictorial library etc. to quote some.

Importance of Research Projects:

Besides the therapies innovated and activities created , the author realized the need for taking up research projects in collaboration with international organizations. As such she approached Dr Giuliana Galli Carminati who initiated to work for collaboration with Lebenshilfe starting from 2003 to 2013 with the units of Psychiatry for persons with Intellectual Disability of the University Hospitals of Geneva , Switzerland on psycho educational approaches and for the validation of the Aberrant Behavior Checklist (ABC) in Telugu which benefited most of the parents and families of Lebenshilfe who

are uneducated and unable to understand the English Literature to respond to the difficulties in the assessment of persons with intellectual disabilities (Aman et al.1985) .

SUCCESS STORIES

Stepping Successfully into the Society, Lebenshilfe's Notable Achievement

1. Mangamma, a mentally challenged girl turned into a challenging family housewife after receiving useful, meaningful and purposeful training from Lebenshilfe for over 20 Years and made her fit to get married and to lead a normal life. She left Lebenshilfe successfully and entered into the society with the same human dignity. Now she turned into a proud mother also. Besides taking care of her baby, Mangamma is also holding a sense of responsibility in assisting her husband in the provisional shop and her in-laws in the kitchen as well as in other household activities.

Her brother Venkat, is also a mentally retarded, and still attending Lebenshilfe to receive training to become a useful person.

2. Another trainee Rajesh married a physically handicapped girl whose parents having greater problems for each day meal. His father's proposal for wedlock solved the girl's problem for food and boy's problem for sex-related needs. Rajesh attended Lebenshilfe till he acquired independent skills through vocational units and now working in a public restaurant on monthly remuneration basis. Rajesh turned into a proud father to a four-year old son too. Outcome: Success.

3. Success Story: Ramudu and his wedded life

26-year old mentally handicapped is lucky to marry Malla Rani, a normal person on 12-02-2005. Ramudu who is receiving training from Lebenshilfe for the past 19 years is presently attending the sewing section to learn the technique of stitching dresses etc. as part of his vocational activity. Having had an arranged marriage he has not faced any problems with regards to his wedding proposal. Rani wants to continue her services as a nurse in a private nursing home. But the family of Ramudu asked Rani not to attend her job and restricted her to stay at home. Ramudu, says he wants to continue, coming to Lebenshilfe to learn sewing and tailoring work to earn some money to take care of his wife. That is his hope. His wife Rani, says she has married Ramudu, though a mentally retarded out of her willingness. She said, her

husband Ramudu sounds an innocent person and does not know many things as other normal persons in the society. However she married him with a hope that she can train him to obtain considerable change suitable to lead a normal married life.' That is her confidence.

4.Success Story of Satyam,a multiple handicapped - Skill Training as an intervention produced awesome outcome.

Satyam joined Lebenshilfe at his age of four. Being a multiple handicapped he turned into a big burden to the entire family. His parents found no way except leaving him to Lebenshilfe's care in view of their bitter poverty. Despite his communication disorders, behaviour problems, hearing and visual impairments he obtained skills necessary for independent living.

His achievements are better expressed through his remunerative job placement at Lebenshilfe as carpentry instructor. When people got frightened to recruit him, Lebenshilfe initiated to give him a life. The strength of his vocational skills acquisition speaks volumes of appreciation from public about his excellence in making wooden vegetable models.

Siva Sankar : Emotional Issues- A Living legend of Lebenshilfe:

Lebenshilfe has taken up Siva Sankar into its fold at his age of four years. He was aggressive and highly emotional with self-injurious behaviour by the time of admission. In due course of time he lost his mother due to cancer and father could not take care of him due to severe health problems. His intolerable behaviour frustrated his only brother resulting total rejection. His parent's death further led him to awful behaviour problems. Lebenshilfe's training with set goals started yielding good results, helping him leading for income generation. Today Siva Sankar is turned into a responsible person, a good artist, an excellent dancer occupying a key role in the logical group, assisting kids as well as staff. Training through Lebenshilfe's theatre helped him a lot to bring his emotions under control and to earn pocket money to meet his daily needs

34 year old Siva Sankar is an emotionally disturbed person. His mother's fatal death left him to his brother who pays no interest in his welfare. Poverty coupled with the aggressive behavior of Siva Sankar compelled his brother to neck him out of home. He has communication difficulties also. His mood often goes off when his demands are

not met. He lacks emotional balance. He threatens teachers at school that he commits suicide if his demands are not met. The total negligence of his brother completely disturbed his behavior. He always searches for someone who loves him. He makes good drawings. He developed some sewing and carpentry skills. He is unable to develop social contacts. Relations do not allow him to visit their homes. His living became a big challenge. He has difficulty to meet his basic needs. His needs for love and affection were also grown with his growing age. He is fond of being with a family.

Factors affecting functional abilities: Missing love, lacking affection, having no friends, unable to form social networks, peer groups rejection, relations refusal, siblings arrogance, resulting beating others without sufficient cause, committing mistakes intentionally such as spoiling the dresses while stitching, tearing the drawing sheets while drawing, spilling the colors while painting etc. running out of school premises, wandering in the streets, lacking interest in self, non-participation in cultural and sports activities, etc.

What Siva Sankar's Sibling says?

We are greatly frustrated with his behavior. We are not prepared to receive any more insults from neighbors or relations. He lacks emotional balance causing unbearable nuisance. Our relationship was gone with the death of our mother who died with cancer. We believe that, he is responsible for all the troubles in our family. We are afraid of his behavior threatening either to kill himself or to throw things with force against us.

Some children love their school and teachers more than they love their home and parents. They are abiding to the affection and develop a sense of attachment with the school. Often parents come with a complaint that they are not able to control their kids at home. Experiences proved that they should be taught in the manner they like. Children love to participate in religious-related activities and sports. These situations are helpful to mould them to moderate behavior

Strategy: to promote emotional balance: Method: Art therapies:

Art therapies: therapies helped Siva Sankar develop psychologically to attain emotional balance. Drawings and paintings of Lord Hanuman, his favorite God from

'Ramayana-Mythology' and his role-play as Hanuman in classical dance ballet helped him to attain emotional balance. Lord Hanuman who is an embodiment of emotion attracted him. Stories and movies on Lord Hanuman brought considerable change in Siva Sankar. Gardening activity resulted in release of tension and increase of love for the nature besides attaining occupational health. Involvement in cultural programs provided a chance for expression of hidden talents, leading to emotional satisfaction.

Power of love: Key for the success:

People like Siva Sankar needs unconditional love. Showering such love works wonders. Expressing affection brings amazing results to increase the decreasing skills. These people are abiding to emotional connections, touch and eye contact. They give greater response to a smaller smile and an affectionate hug coupled with motherly love. Siva Sankar now turned into a valuable contributor. This is the key for success.

PATHWAY TO INDEPENDENT LIVING: A Success story of KAILASAM

"Tie him up tightening his hands and legs and throw him into Bay of Bengal". This was the advice given by close relations. "Let him die in the sea waters, there ends the matter, strongly supported by kith and kin". Yes, foolishness is bound up in the hearts of my relatives - says Kailasam's mother.

I do agree that my son Kailasam turned into a greater burden to all of us while we move on for begging from door to door for livelihood. He started growing physically but lacking behind in everything. There was considerable delay in his mile stones of development. I approached medical doctors taking my son to a Govt. Hospital where I was shocked greatly and felt like forcibly thrown from the peak of a mountain into a valley.

I realized that he is of no use and I cannot take care of him in view of our poverty. I am not educated and do not know how to handle this boy. I was told that he was a child with special needs and to be paid personal attention. How come it gets possible? Who helps me in this confused and helpless situation? With this million dollar question slowly I started locking myself in a bleak place. All my thoughts were getting cantered on my son but found no way to come out. I slowed down even my profession of begging which caused agony of the other family members and allocating more time for my son. I rejected bluntly to follow their advice. None of them could realize how hard it would be to implement their advice.

My love for him as a mother couldn't allow me to be inhuman to kill this boy. I love him despite his disability i.e. mental retardation. Out of my love and fascination to Indian Classical dance, I named him after KAILASAM. I know that my son can't walk, can't talk, has no toilet control, no communication, and no ability to comprehend things, unable to follow instructions, fully dependent and needs to be carried for mobility from place to place. Adding to this he often frustrates others with his intolerable behavior, pinching, biting, tearing clothes, pulling hair, pelting stones what not, causing inconvenience and greater hindrance for our vital activity connected with our livelihood.

About Us

We belong to 'PAGATI VESHAGALLU' community. We live on 'BEGGING' and it is our main source for livelihood. We go begging in groups from door to door depicting ourselves as characters of God related to Indian mythology. Lord Rama, Krishna, Hanuman, Shiva & Parvathi etc. are some to quote. We follow some traditions basing on a divine belief. We receive used clothes, rice and other things necessary for living from people in appreciation of our appearance. Day time (PAGALU) is our choice for begging with makeup (VESHAM) and hence we derive that name, 'PAGATI VESHAGALLU'.

What I did and how it helped?

It is in this situation I left my five year old son Kailasam at Lebenshilfe, placing him at the feet of its Founder Saraswathi Devi (Sarah), with no knots tightened to neither his hands nor legs. Her acceptance for admission showed me a way to come out of the bleak place where I was locked myself. Training at Lebenshilfe empowered me and my son and strengthened me to face the challenging situations all by myself.

As a result

Today my son Kailasam, was developed with full potentiality. Lebenshilfe trained him for reality and success, instilling moral values, moulding his behavior suitable to fit into the community. Now he walks even faster than people criticized, talk, sing and play musical instruments better than those advised me to put him to death.

He could learn rhythm and started earning his pocket money by playing DOLAK and TABLA (the Indian traditional music instruments), participating in music concerts in public places during local Deity Festivals and receiving recognition and acceptance as a worthy human being. Now girls from our own community are offered for wedding and in near future I am quite confident that he walks into the society together with his wife to lead a normal life like anybody else.

Lebenshilfe: What it means to all of us? Lebenshilfe gave my son a life with a meaning, a life with human respect, a life with human dignity and a life that fits him in the human society. That is why, for us, Lebenshilfe is a TEMPLE and its founder a 'GODDESS'.

Freedom and dignity for everyone

From the beginning, Sarah's goals have been very clear: mentally handicapped people are not "incapable and non-productive" persons, like many people seem to think. They are differently abled, they can develop other skills and they must have a status in the society. So her first aim was to make sure that they all would get economically independent, by giving them an adapted education that would allow them later to earn money and be free. "Every mentally handicapped person has the right to live a life of quality and dignity", she insists.

The children learn to read, write and count, they get a general instruction, learn about science and religion, drawing and painting no matter they are children, growing to age or ageing and the goal is that everyone can develop his own personality. Carpentry, gardening, sewing, bookbinding, cooking, toy making and candle making can be learned and enable the children to find a job later on. The residents also make sports and Special Olympics are organized regularly. Families are asked to participate in all these activities and in the daily life at Lebenshilfe, in order to increase their knowledge about taking care of their handicapped children.

Lebenshilfe is also organizing seminars, workshops and symposiums, together with specialists of other countries. for Sensitization on a large scale

New therapeutic approaches

Lebenshilfe is really using modern therapeutic approaches for the children, and in Europe people are wondering how all this can be achieved in a country like India. It is mostly due to Sarah's energy, intelligence and engagement, but also to her generosity and confidence. She is restlessly looking for the best solutions for her residents, travels regularly to Europe where she makes new contacts, invites specialists from other countries and introduces new therapies like the Tiger dance therapy that she invented herself. According to their personal needs, the handicapped people will get physiotherapy, speech therapy,

music therapy, yoga and dance therapy, sports and games and even snoezelen therapy

Artistic activities are also very important: singing, dancing, painting, playing theatre are everyday activities and festivities are very frequent. "Life is rich", says Sarah. "Mentally handicapped people should be able to live this richness like we do. My visitors all ask me how it is possible to achieve all this in a third-world country. My belief is that you can get the same results under a tree as in a high-tech building. It's only a question of humanity".

An outside look on Lebenshilfe

We had the chance to meet Sarah during her European trip last summer. A few hours spent with this very special woman are unforgettable: she speaks about her experience - in fact the project of her whole life - with such a charisma that you just would go to India and see by yourself! Although, the day we met, Sarah's eyes became sad for a short while. She just had been informed that the Indian government was going to reduce its financial contribution to Lebenshilfe, unless the collaborators were trained as educationists. Which is impossible, due to financial reasons of course. "When I was informed about that, I stayed in my room for three days and three nights. I looked into myself and I asked God to show me the way. He never deserted me, and I know that there will be a solution". Then she organized a reunion with her collaborators. All of them, educationists, teachers, cleaning and kitchen personnel, bénévoles, told her: "we are going to stay with you". And they accepted to have their salaries reduced during the next three years. In between, Sarah, restless, went on the road again: in Europe she has multiplied contacts, proposing different kinds of partnerships and inviting everyone to come and visit her.

"I want to serve", that's what Sarah decided when she was six years old.

To accept, to integrate mentally handicapped people and to offer them a life of quality is her personal way of serving.

"But", concludes Sarah, "in the matter of handicapped people, families, communities and governments also have their part of responsibility. It's only together that we will give these children a better life".

Lebenshilfe developed from scratch to its today's heights due to several helping hands. starting from local government to central government, besides the help being extended by International experts and associations. Lebenshilfe acknowledges all those who are strengthening its serving hands profoundly.