

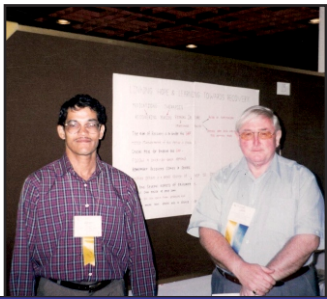
The Flourishing Institutional Life in America

(For Persons with Mental Illness)

Prof. Dr. Anil Vartak



Eklavya Foundation for Mental Health, Pune



The author with Jim Crowe of WFSAD



With Verbanik, Founder of Schizophrenics Anonymous (SA)



With Dr. Abraham Low's daughter



With the CEO of SA



With the office bearers of Self Help Clearing House



A meeting of S.A under progress

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Author:

Prof. Dr. Anil Vartak – 9503710859

avartak@yahoo.com

Publisher:

Dr. Anil Vartak

(For Eklavya Foundation for mental health)

A-14, Siddhant Apartment, 312, Shaniwar Peth,

Pune 411030

Printer:

Splendour Graphics

298 Shaniwar Peth, Pune 411 030

Illustrations:

Asim Deshpande and Poornima Kote

First (English) Edition: January , 2022

Price: Rs. _____.

This book is dedicated to

Late Bob McIntyre who served as the President of Recovery International and his wife Dot McIntyre.

The McIntyre's were warm and welcoming. Their hospitality provided me the opportunity to learn the Recovery method. They extended support for the growth of the Recovery method in India and across Asia.



Foreword

Dr. Anil Vartak was running the Ekalavya Self Help Group of Schizophrenia Awareness Association since 1997. He however felt constantly pricked by the feeling that the group was not significantly benefiting patients. He intensely felt that the group should find a proper direction, that routine monotony should be avoided and that it should benefit those affected in a better manner. Coincidentally around the same period he came to learn of self help groups in America around this time and this was followed by an invitation to visit the US. During this visit, he was able to attend several groups, gatherings and institutions.

Anil Vartak had in effect completed this work in 2001 itself but due to some reasons, could not publish it at that time. We are today delighted to publish it in the form of this booklet. At a time when not only in Pune but in the whole of India, people had not even heard the names of such institutions, it was no ordinary feat by Dr. Vartak to search and compile a list of such institutions with the help of the internet, which had then been recently introduced in the country. Issues regarding mental illness have been raised in India right from 1950. However, till then, there was no sign of any attempt to conduct an in-depth study of the changes required at the level of patients and their families, that is, from the social angle. Making excellent use of his own illness as the backdrop, Vartak created a unique platform for the progress of SAA, where there were many choices that could be availed to decide the direction of SAA's progress. It was with this motive that the US visit took place.

Mere availability of funds is not enough for any institution. It also needs a vision to facilitate its progress. It is therefore

SAA's good fortune that right from its inception, there were such experienced individuals associated with it. The journey itself took place in 2001. Reading about it today, one may perhaps discern lacunae at some places. We too had contemplated effecting a few changes, given today's scenario. However, as the method of functioning of the institutions mentioned remained unchanged, we decided to retain the report in its original form.

We feel this report will in effect be a valuable document for organizations working in the field of mental health. Anil Vartak is still in touch with some of the organizations mentioned. Dr. Vartak would be glad to provide information or guidance regarding these institutions in America and give advice on their programmes and projects.

Neelima Bapat,
Vice President, SAA

Gurudatt, Kundapurkar,
Adviser, Eklavya Foundation.

Smita Godse, Secretary,
Eklavya Foundation for Mental Health



॥श्री॥

Musings

‘The value of a man becomes nil once he is bedridden.’ This thought did not escape even from my mother’s mind after she was diagnosed with deadly cancer, in spite of having been a medical professional and having lived a complete life. Any serious illness throws a person far away from the mainstream of life. If such a serious illness were to affect the mind and if it happened when the person was young, it would be difficult to imagine to what extent the person would be away from society and the life stream. Schizophrenia is one such serious mental illness that can result in severely weakening the affected person’s transactional abilities. ‘Ekalavya Foundation’ are engaged in the significant task of rehabilitating seekers of wellbeing (Shubharthi) by using the self help technique along with medicines. This booklet is an invaluable guide to those who wish to know more about this work and the ‘Recovery Method.’ With regards to treatment facilities and social rehabilitation of such persons, India lags far behind America and other western nations. Dr. Vartak has in this booklet, systematically elucidated what the Indian health care system has to learn from various American institutions and people’s initiatives. In this booklet, Vartak Sir has in brief, mapped how the functioning of patients , their families, the patients groups, the society at large and the government health care machinery could be more effectively streamlined.

Internet services in India began in the last 4-5 years of the previous century. In fact, I remember my brothers and I had gone to some place in Pune in 1997 to see the internet!!!

After a lot of effort, we got to see a few coloured pages on a computer screen. In fact, it is interesting to read how the study tour of America took place with the help of just the internet and good-natured persons like Dr. Jagannath Wani and Mr. McIntyre when 'Windows' and 'Icons' were fairy tale concepts and even in areas like Parel and Dadar, the internet was priced at Rs. 2 per minute. It is possible that Vartak Sir received the legacy of research from his father Dr. Vamanrao Vartak and one cannot but notice from this booklet that even after being afflicted with schizophrenia, his curiosity and inquisitiveness have not diminished one bit.

Dr. Anil Vartak is a huge inspiration not only for persons with schizophrenia but for all who work with social consciousness. His views on mental health and the rehabilitation of persons with mental illness have been beautifully expressed in this booklet. There is no doubt that this booklet will be very useful for experts and laymen as well as patients and social workers.

Dr. Rahul Sidhaye

M.D. Ph.D.

Psychiatrist and Health Researcher



Preface

I have been working in the field of mental health since 1995. Initially, I joined a self help group to derive some benefit for myself. We later created the Ekalavya Self Help Group in 1997 for patients and their family members. Around the same time, we joined the Schizophrenia Awareness Association or SAA, which was established by Dr. Jagannath Wani.

Though we were running the self help group with enthusiasm, it was constantly felt that there should be a defined method to run it. At that time, our family friend and Dr. Wani's associate Mr. Anant Gupte proposed that I should visit various institutions in America. In fact, I had no thought till then of ever going to America. Gupte uncle wholeheartedly encouraged and inspired me with the enthusiasm to make preparations for this trip. In those days, the internet was a new and costly entity in Pune. From May to July 2001, I launched a quest to identify various organizations in America and their plans and projects. I began to look at organizations in various American cities and the transport facilities available. Today, when I look back at those days, I realize that I could manage all these only on the strength of my youth and my passion.

To start, Mr. Bob McIntyre, who was then the President of Recovery International, invited me to stay at his house to get trained in the recovery method. Once it was decided that I would go to learn the recovery method, I started planning to visit other institutions one by one. I kept the map of America in front of me while making the sequence of my visits. Once my going to America was finalised, Dr. Wani provided me the funds to travel by air. It is difficult to get an American visa, that too, when one is young. I did not have any letter of employment or an invitation from famous or important

institutions. The invitations I had were from small and less known organizations. In this dire situation, my old friend and founder of Sihaya Self Help Group Dr. Mira Dakins-Sadgopal rushed to my rescue. She arranged through her brother Henry Dakins in America to provide me valuable documents and substantial funds for my day-to-day expenses and travel in America. Not just this, she also wrote to families known to her at various places and arranged for my stay. My friend Dr. Vinayak Sholapurkar wrote to his uncle Dr. Jagdish Markale and Dr. Shakuntala Markale and the doctor couple helped me in all ways during my American sojourn with love and kindness. My sister Dr. Jayashree Satavalekar and Mr. Mukund Satavalekar, who were in New Jersey also assisted me with great affection. I was able to travel and gain experience for 2 – 2-1/2 months only due to the help of Schizophrenics Anonymous, Bob and Dot McIntyre and his Recovery organization, NAMI, the organization of family members of patients and many others. My American visit depended entirely on the goodwill of all these persons and institutions. I am grateful to them all.

Mr. Ramesh Dighe has been my associate from my Sihaya Self Help Group days. This booklet began to take shape in my mind after a series of discussions with him. Mrs. Neelima Bapat, who is an office-bearer and part of SAA from its inception, went through the draft of this booklet several times and suggested significant improvements. Likewise, Mrs. Smita Godse, Mr. Anand Godse and Mr. Gurudatt Kundapurkar read the draft and made useful suggestions. I thank all of them from my heart. The Vartak family has always encouraged my beyond-work activities. I am very happily indebted to them.

The college where I was working as a teacher, Sir

Parashurambhau College, very kindly sanctioned me leave to go to America, thus removing a big hurdle in my travel. Miss. Poornima Kote, a psychology student of the college, helped design an attractive front cover for the booklet. My sincere thanks to her and to Splendour Graphics, the printers. The cost of producing this booklet has come from the donation made by my sister and well-wisher from New Jersey, Dr. Jayashree and Mr. Mukund Satavalekar couple. I also thank my friend Mr. Ravindranath Chandran, Trustee of SAA for translating this booklet in to English.

The birth of SAA and my entry into this field of work happened more or less at the same time. Therefore, I view SAA with the fondness of an old classmate. Even so, I must formally express my heartfelt gratitude to all the then and present office bearers of SAA.

Finally, when I went to America in the year 2001, changes were beginning to take place in India in the arena of mental health. Naturally, I dreamt of initiating various projects in India on mental illness and mental health under the aegis of SAA after my American trip. Some of these have partly materialized while others have not even taken off. Though I do feel a bit sad over this, it is definitely not a major regret. There is still a lot of satisfaction to be derived from having dreamt and having helped materialize at least some of those dreams. Though nearly 20 years have passed since my American visit, a lot of changes are required even today in India. Even if this booklet proves an inspiration to a few to work in this direction, this will be a source of great satisfaction to me.

Anil Vartak

(President, Ekalavya Foundation
for mental health)

The Flourishing Institutional Life in America

For Persons with Mental Illness

Self help groups are established in order to facilitate persons facing the same problem to come together and exchange mutual experiences. The social mindset however, has not accepted self help groups of persons with mental illness with the readiness with which they accepted self help groups of persons with heart problems, cancer or diabetes. (In reality, more than these other illnesses, rehabilitation and self help groups are useful for persons with mental ill.

Even so, this concept isn't accepted by the society. There could be many possible reasons for this. Coming to one such group is tantamount to openly admitting to one's illness. People find it humiliating to openly admit one's illness because of the social stigma attached to it. After going to a group, would we be able to open up and frankly talk about the type of illness, the severity, the medical treatment, one's experiences etc.? One is reluctant to mingle with unknown people and disclose these details.

It can also be said that another important reason for non-acceptance of the concept of self help group is the apprehension that is in the minds of the caregivers of persons with mental illness. They are not confident that self help groups too know what professional psychiatrists state with authority. Likewise, they are not sure that regularly attending self help group meetings would result in improvement.

It must be made clear that the self help group is not an alternative to medical treatment. Due to mental illness, a person's interaction with others and other such skills become

diminished and a gap is created between the person and the society. Going to a self help group boosts re-establishment of these skills. (Only by remaining in the social mainstream is rehabilitation possible.) I was associated with one such self help group that was working for persons with mental illness and their caregivers since 1996. At first, I joined the group for my personal benefit but then, with the idea of expanding the group and its scope, I set up a new group called 'Ekalavya.' This group later became a part of Schizophrenia Awareness Association or SAA.

Working with the group for 5-6 years, we always felt that though we were working, the group had no defined method of functioning. The group met for two hours every week. The assembled patients spoke and discussed among themselves. As a result, their burden became lighter. As a matter of fact, their narrating their sorrows and discussing them is a never-ending process. Therefore, it became necessary to find a method by which members would see constant improvement in themselves.

Initially, the discussions in our group had no such direction . We therefore strongly felt that we were repeatedly involved in expressing our own problems. There was not much improvement in the patients . It became clear that the same number, the same persons and the same process of listing their worries and sorrows brought about a sense of ennui.

Under the circumstances, people in the group began airing their thoughts that if the group was to progress, the objectives should be clear and there should be a documented method of running the group. Even as we were airing our views on what could be done so that the group would be of maximum use to patients , we received

information about such groups in the US. We obtained more information in this regard through the internet. Emails were sent to persons in the field of self-help groups in America and cordial relations were established with them.

Consequently, an invitation was received in 2001 from Bob McIntyre, Vice President of 'Recovery Incorporation.' Not just this, but he even arranged for my stay at his own home. Likewise, Dr. Jagannath Wani, President of 'Maharashtra Seva Samiti' (MSSO) in Canada and Henry Dakins from San Francisco provided substantial help in meeting my travel and other expenses.

Once my going to America was finalised, I began pondering on what I could achieve during the trip. The following points were prominent in my mind:

1. The aims and objectives of our group should be clearly defined.
2. We should develop skills that would contribute to more streamlined functioning of our self help group.
3. We should be in a position to help and encourage development of teaching programmes and tools that would promote the aims and objectives of our group.

Accordingly, I decided to study the functioning of self help groups and related organisations in America working in the field of mental illness, how the groups were formed, what their underlying philosophy was and how the volunteers and executives performed their duties.

I was not acquainted with anybody who had done such a study. Therefore, I was compelled to rely on Bob McIntyre of Recovery regarding going from one place to another, how to go, whom to meet etc. Hence, on my part, I tried to plan my trip itinerary. I used the internet extensively for this purpose.

Today, there are so many guidelines available through the internet for travellers to an alien, advanced country like America. Detailed information regarding the American Railways, the addresses of various organizations, the phone numbers of contact persons, maps to reach places and myriad other data can now be easily obtained. I must particularly mention that the data I obtained from the internet was accurate to even the minutest detail. For example, the same person whose name and phone number were mentioned, existed in reality. We don't get to see such up-to-date information in the official websites of our government departments. Even if a Chief Minister had been replaced by another several months ago, the old name would still be ruling in the official website. I did not see this anywhere when it came to American websites.

I landed at New York's John F. Kennedy international airport on May 29, 2001. Due to the availability of accurate information and the meticulous planning done with its help, I was able to not only visit many organizations working in the field of mental health and some exhibitions but also a few tourist spots in my sojourn of barely two months. I had the opportunity to visit an exhibition on the brain. How I was able to do all this in such a short span of time was a surprise not only to my acquaintances who lived there but to me as well!

Collecting all the experiences derived from visiting institutions and meeting people working in the area of mental health, I came back to India on July 17. As regards support groups of mentally ill persons, America is far ahead of us. Support groups have been running there for over half a century. In fact, this has now become a tradition there. During my stay in America, I was blessed with a comprehensive view of this tradition. Among the main

groups I saw, I must mention the following which were noteworthy: Recovery Incorporation, Schizophrenics Anonymous, National Alliance for the Mentally Ill (NAMI) and New Jersey Self Help Clearing House.

This booklet is the result of my desire to make a detailed record of the persons I met, the discussions I held, the organizations I visited, the conferences I attended and the exhibition I saw. Recovery Inc. or Recovery Incorporation is a name that one might associate with an industrial organization. This self help support group was established in 1937 and today over 700 Recovery groups are functioning in America. The founder of this institution was Chicago's Dr. Abraham Low, a qualified neurologist. In his long stint as a medical professional, he treated thousands of mentally ill persons. To bring about improvement in them, he performed various experiments. As a consequence, he observed that total recovery could not be achieved by medicines alone. The ill person should also be actively involved in pursuing the path of progress.



American Self Help Group: Recovery Incorporation

Tormented by the thought of how membership of this group should be, Dr. Low set up a group of mentally ill persons. He provided the guidance for the group in the beginning. In those days (1930), even American psychiatrists were diffident of the success of such self help groups. Even so, ignoring them, Dr. Low went ahead with the work of the group. Gradually, through experimentation, trials and errors, the group began to evolve a system of functioning.

The Recovery Method

In this method, to start with, some parts of a book written by Dr. Abraham Low are read out. There is however, no discussion on it. I discussed this with 'Recovery' executive Bob McIntyre. He clarified that mentally ill persons coming to the group are extremely sensitive, plus their mental balance is skewed. In such a condition, if there were discussions on such information, the confusion in the minds of the mentally ill persons would be exacerbated and their confidence in the recovery method would become shaky.

After some parts of Dr. Low's book had been read, the next stage of the meeting would be for each mentally ill person to narrate an uncomfortable experience that took place in the period between two meetings and how the person dealt with it. The narration of this experience has four steps:

1. Very briefly narrate the experience or occurrence.
2. During the experience, what were the unpleasant physical and mental symptoms and changes noticed, like sweating, tremors in hands and feet, feeling of despair etc.

3. The person has to state which recovery method principles (tools) were useful in overcoming the difficulty.
4. The person has to tell what could have happened if he/she had not been aware of the recovery method and how it became possible to deal with the situation with the help of the recovery principles. How the situation was contained, the earlier situation, the present situation and the difference between the two have to be stated. After this, the Shubharthi has to congratulate himself/herself for the effort.

It had also been the earlier experience in our group that when any person was narrating a particular incident, it was embellished extensively with unnecessary information. Thereby, the listener would often wonder exactly what the incident was that had caused the narrator, mental trauma. To avoid this, Recovery has laid stress on brevity in stating the incident. Since it was required to identify which aspect of the incident caused mental discomfort, it became possible to comprehend the reason for the mental discomfort. Identifying this cause is an important part of the process of enabling the Shubharthi to recover from his mental illness. By this, the person gets a boost towards adopting a positive attitude.

After this, one has to state which recovery principles were useful or how they were used. This is referred to in Recovery as a tool. There is a list of several tools or principles in Recovery for help during various incidents and circumstances. Had one not been aware of these principles, what could have happened and the difference that was effected by using the Recovery Method become clear to the mentally ill person.

A member of the Recovery Group keeps congratulating himself/herself for the efforts he/she took to use this method. While an incident or circumstance is happening, locating that aspect which troubles the mind is called recovery spotting. A mentally ill person derives the true benefits of the Recovery Method when he/she locates the cause of his/her mental discomfort, uses the proper principle for help and then appreciates himself/herself for making the effort. Thus, a way to come out of mental illness becomes visible. Even those with normal states of mind and not mentally ill, knowingly or unknowingly use the positive approach of the Recovery Tools for help with natural ease. Since this natural tendency is absent in persons with mental illness, these tools for help have to be etched in their minds. This habit is inculcated through the four recovery steps. The person gets used to using the proper Recovery Tool for a particular situation and the difference it makes to the person is clearly seen.

The 'Recovery' group is open to persons with all types of mental illnesses. Different illnesses manifest different symptoms. The Recovery Method places accent on how to



prevent these symptoms from getting out of hand during troublesome circumstances and how to deal with them. The method is based on the symptoms. The type of illness or the medicines used are not discussed.

In this manner, during meetings, all members narrate their experiences to one another and the action they took at that time, thus mutually providing the confidence to improve. Nobody criticizes a member after he/she has completed his/her narration, nor do they offer suggestions or advice. However, the important positive principles in their narration are referred to. It can be said that the unique speciality of the Recovery Method is the progress made on the path of wellness through improvements made in minor day-to-day events and incidents. In short, the foundation of the Recovery meetings is identification of the circumstances that cause discomfort and overcoming the problem by using the appropriate Recovery tool for help.

Schizophrenics Anonymous (S.A.)

By name and in some other aspects similar to Alcoholics Anonymous, Schizophrenics Anonymous was founded in 1985 by Mrs. Joanne Verbanic. The S.A. group is exclusively for persons with schizophrenia. As a result of the social neglect she experienced due to schizophrenia, Mrs. Joanne set up this self help support group.

Once, while narrating her experiences, she said that about 25-30 years ago, even in America, there was great stigma regarding mental illness. Though employed in a famous organization like Ford, she had to face a lot of tensions and pressures at her work place. With its main office in Lansing, Michigan, in two decades following its establishment in

1985, Schizophrenics Anonymous (S.A.) grew to over 150 branches in America and Canada.

While Alcoholics Anonymous has propounded 12 steps towards improvement, S.A. has put forth six important steps for the improvement of persons with mental illness, taking into concern their major hurdles.

1. **I surrender:** I accept that I suffer from mental illness and I cannot face the problem alone. I need help.
2. **My priority:** I give priority to becoming well. I have the freedom to make choices towards improvement. The decisions I take will have their consequences on the quality of my life. I take total responsibility for my decisions.
3. **My faith:** It is my confidence that there is great energy to improve within me. I shall use this energy for myself and for others.
4. **I forgive:** I forgive myself and others for past mistakes.
5. **My awakening/awareness:** I have come to understand that due to my erroneous and harmful thoughts, I generate the feelings of despair, sorrow and fear. I am prepared to change these erroneous thoughts. By changing them, my life will become happier.
6. **My resolution:** I have decided to dedicate my life to God (or as preferred by the person).

By these six steps, S.A. has constructed a definite framework for its functioning. A direction has been shown for the ill person's rehabilitation. One more aspect is that members of this group have been bestowed with a lot of freedom. Every group in any place can plan its own manner of functioning. Myriad paths can be sought to come out of mental illness.

There are no rigid rules governing the give-and-take of experiences.

Persons with mental illness think negatively at times and positively at times. Not binding them under any strict framework and allowing them to present their thoughts in the manner preferred by them proves beneficial to them. Sharing one another's experiences frees the path for suppressed emotions. Requisite emotional support for improvement is found in fellow-members and the tendency to view one's problems with boldness and maturity is encouraged.

The website of S.A. on the internet is a fine example of how the website of a support group for mentally ill persons should be. New developments regarding mental illness taking place in the medical field are regularly featured in the S.A. newsletter. The weekly meetings of S.A. are coordinated by trained leaders of the group who has had experience with schizophrenia. I was unable to attend a meeting of S.A. However, I was able to be present at the training session of group leaders at East Lansing, Michigan. This training was very well-structured. Not only old group leaders but group leader aspirants were also included. These trained group leaders form the main strength of S.A.

Picnic for Shubharthis

One noteworthy programme of S.A. is the picnic for patients. I was given the opportunity to participate in one such picnic organized by S.A. People had come for the picnic in 5-6 cars. They had brought plenty of food and drink with them. We had gone to a garden on the banks of a lake about an hour's drive from Lansing. There were hardly 25-30 people who

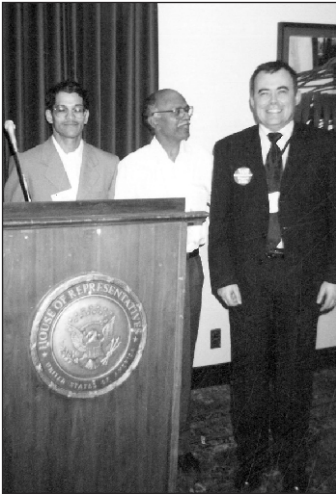
attended. It was biting cold and raining as well. There were many small shelters that had been erected. They contained small stoves, ovens etc. There was space to keep the things that had been brought. Even Joanne Verbanic, founder of S.A. and all of 70 years, had participated in the picnic with great enthusiasm. When she met me, she enquired of me with great sincerity. Overall, the picnic atmosphere was very encouraging. The picnic included the happy event of a forest meal. There was no programme other than free frolicking and jokes, general conversation and of course, food. I did not even know how the 4-5 hours of the picnic went.

It is one of the specialities of American society that they can freely and openly indulge in hearty laughter and frolic without any restriction. However, care is taken that during such comic phases, no weaknesses are pointed out or anyone criticized or even jokingly addressed in an insulting manner, so that nobody is hurt. Generally, in their day-to-day lives, mentally ill persons are usually neglected, as a result of which they come under a lot of stress and pressure. Under these circumstances, it must be said that such an open atmosphere can be highly conducive to their recovery. In such an atmosphere, one can see ill persons coming into bloom. Persons who have recovered from illness voluntarily take the trouble to attend these picnics. They mingle with ill persons. Due to the mixed group of persons yet to recover completely and persons already recovered persons with illness get motivated to become better. Because of their association with recovered persons, patients attending the picnic gain confidence that just like them, they too can recover fully.

National Alliance for the Mentally Ill (NAMI)

This is an organization established by caregivers of persons with mental illness and functions at the national level. It was set up in 1979 and has its main office in Washington D.C. It has a membership of over two lakhs and is spread throughout America.

NAMI is engaged in multifarious ventures such as encouraging self help groups, disseminating information, training caregivers, enhancing their care-giving skills for patients, publishing literature on mental illness, fighting for justice for mentally ill persons etc.



If there is a mentally ill person at home, those who are their caregivers face emotional struggle, sadness, and social ostracism. Due to the emotional ups and downs of the person dear to them, those who look after them also begin to collapse like the mentally ill person. They get exhausted struggling with

their tensions. To top it, they have to face everything alone.

At our SAA meetings in Pune, caregivers accompany patients. They have their separate meetings at the same venue. I mentioned this experience at a conference in America. They were surprised by this concept. After listening to the experience, someone casually remarked that in this regard, India was ahead of America. In America, there are altogether separate groups for caregivers and patients and at times,

they adopt conflicting roles. There is no system or practice there to have caregivers and patients sit together or even at the same place. In this background, they must have seen the coming together as something laudable.

I was present at the five-day conference of NAMI at Washington D.C. The conference was altogether a different event. The conference was held in a spacious hall. It was not like what we get to see here with luminaries crowding the stage and the lay audience seated in front of them in the hall. Large round tables were kept spaced out in the hall. There were food items kept on the tables. Representatives seated around the table were enjoying the eats on one hand and on the other, responding to the speeches at the conference with equal fervour. There were two large closed circuit TVs as well in the hall.

Diverse topics were included in the agenda of the conference. Along with delegates from many other countries, there were over 1000 delegates from NAMI who participated. These NAMI members were participating in the discussions on various issues with gusto. I could see an awakening among the assembled care givers of persons with mental illness.

Three or four members of the American Senate had proposed improvements in the insurance rules regarding medical facilities for mentally ill persons. These members were also present at the conference. They forcefully presented their stand regarding the new rules. One of them gave a passionate speech that was received by delegates with thunderous applause.

If something is to be demanded or what has been demanded is to be received, it requires a large organization and pressure

group. This principle has been executed excellently by NAMI. NAMI has established good relations with persons in the medical field and with pharmaceutical companies. These companies lavishly sponsor NAMI's conferences and programmes. I noticed that even political leaders made it a point to attend the conference.

New Jersey Self Help Clearing House



This organisation was established in 1981 in New Jersey. This is an organization that provides information on the location of self help groups for all kinds of physical and mental disorders, domestic issues like divorce etc. It strives to enhance the strength of the self help groups. It provides guidance for the setting up of self help groups, in preparing their brochures and informative leaflets, in creating a working pattern etc. From its inception, it has spread its ambit wide and has helped and guided the setting up of over 1000 self help groups. It has also prepared a directory of the contact numbers of self help groups.

The emotional support received from the self help group increases the chances of the patients improvement. Though this is true, one does not see a person who derives benefit from the self help group taking the initiative to either strengthen the group or to set up other such groups. To inculcate and enhance a sense of duty among such persons, Clearing House keeps issuing informative literature constantly. It also clarifies doubts regarding the group's style

of functioning, via Email. It has also expanded its website which provides information on self help groups. Besides, one can avail toll-free telephonic services to contact the organization for information.

Thus, Clearing House has expanded a different facet of mental health related work. By the efficient use of telephone, Email, list of self help groups, creation of websites and other such modern facilities, Clearing House has been spreading information to more and more people. With limited but dedicated executives, Clearing House can be said to be an ideal example of how to reach the maximum number of needy persons.

Mental Health Recovery Center

Mrs. Mary Ellen Copeland and her colleagues in Brattleboro, Vermont, have created a sturdy syllabus to enable patients to free themselves from their illness. The course, which is imparted several times a year, consists of two major parts.

I had completed the first part of the course through correspondence. I was keen on staying there and completing the second part in person. As my trip to America was delayed due to some difficulties, I could not manage this. Even so, after going to America, I made efforts to understand how Mrs. Copeland managed to come out of her own illness. Using this method of getting well, how her belief that others too could regain wellness became stronger was heard by me directly from her.

My observation regarding Mrs. Copeland's syllabus is that she has designed it on the basis of her own experience in managing her mental illness. The curriculum efficiently includes all aspects of the process of progressing from a state

of mental instability and confusion to a state of stability and lucidity.

The principles of self help listed at the end of the study syllabus are extremely useful to free oneself from mental illness. Therefore, even though the course seems to a bit highly priced, it is designed to provide more benefits in less time. It will also be a certain help to those wishing to enter the field of mental illness and make systematic and disciplined use of modern technology.

Exhibitions on the Brain

An exhibition on the brain sponsored by the pharmaceutical company Pfizer Inc. had been organized at the Smithsonian Museum in Washington D.C. It must be mentioned that this was an outstanding attempt to explain the working of the brain in a simple manner. The exhibition provided information in great detail on the brain. With the help of models and other apparatus, the history of the evolution of the human brain, the movement of signals through the nerves, where in the brain are the centres for thought and emotion located, the various stages of development of the brain during pregnancy, how mental illnesses arise when the equation between chemicals in the brain changes etc. were shown. An actual human brain was also kept on display. The



brains of a few other animals and birds had also been kept. There was a facility where one could perform one's own EEG. Visitors were even permitted to conduct a few experiments. Information about the wonderful organ brain was presented in a manner that could be understood even by a lay person.

Some more displays that merit mention were that there was information on the mental illnesses suffered by world-famous personalities from the fields of politics, sports, music etc. The names of well-known persons like Abraham Lincoln and Churchill were included. This was to highlight the fact that in spite of such illnesses, they faced no difficulty in discharging their important responsibilities. The exhibition also expressed regret over the fact that due to the stigma associated with it, very few persons with mental illness come forward to undergo treatment.

Since the letter written by an ex-President to the people of America regarding his mental illness was displayed prominently, it drew the attention of visitors. I must make a special mention of the letter. Without any reticence, with no inhibition, sweeping the social stigma on mental illness aside, Reagan has in clear words, admitted his mental illness in the letter. He also said in the letter that by admitting his mental illness, people who did not come forward would now come forward for treatment and appealed that more and more persons should opt for medical treatment.

In our country, even if a small weakness is pointed out in a great person, emotions explode. In this backdrop, special mention must be made of the graciousness of the people of America. I could not see any sign of mortification on the faces of the American spectators in spite of being shown prominently that a person they revered so highly had mental

illness. I was touched. Mental illnesses are illnesses related to the brain. The person cannot be held guilty for the illness. By stating this fact, the exhibition had attempted to dispel the misunderstanding in the minds of the general public about mental illness and therefore, this attempt to awaken the masses deserves unstinted praise.

After seeing the exhibition, the thought that flashed through my mind was that even in our country, there are institutions like NIMHANS in Bangalore which do great work in rehabilitating persons with mental illness. These institutions have equipment and facilities, funds and persons who are experts in treating mental illness. Why can't such institutions think of organizing exhibitions and other programmes for public awareness? I did ask Dr. Ranganath of NIMHANS who had come for the conference but could not get a satisfactory reply. I even began thinking if such exhibitions could be held in a medical college or a university or even if it could be a travelling exhibition.

Observations

1. **Self help group:** A well-established tradition in America. Though the concept of self help groups is new in India, its philosophy is firmly entrenched in America. There, one sees a chain of self help groups run for specific illnesses, separately for persons with mental illness and their caregivers. The largest among them are Recovery Inc. and Schizophrenics Anonymous (S.A.) Though their philosophy, background and the persons coming to them are different to some extent, there are also many similarities. The method of S.A. is to give a lot of freedom to members to share their experiences and to respond to them. In the Recovery Method however,

experiences have to be told within a defined framework and importance is given to issues encountered in their day-to-day lives in order to encourage them to find their own answers.

One stark difference I noticed between American and Indian self help groups was that in America, people came to these self help groups in the initial stages of their illness while the number of persons coming to self help groups in India after their illness has reached an advanced stage is more. Such persons have very little capability of doing meaningful work. Some of them have dropped out of their studies or have quit working. By sitting idly at home without doing any work, the same thoughts recur in their mind and their illness becomes worse. Some have had to be admitted to a mental hospital while some have had to undergo shock therapy. Some need to be admitted to an activity centre. We however lack such centres and those that do function are very costly.

In America, the opinion of individuals is respected. Since an individual's freedom of expression is a fundamental principle there, people get habituated from an early age to state their opinion. Conversely, the situation in India is such that even a normal person is not accorded proper respect, his words are not even acknowledged and his opinion has no value. Therefore, there is no confidence in his speech and behaviour. In such a situation, how can the condition of a mentally ill person be described? Because of this, those who come to a self help group take a long time to speak and open up. This affects the discussions that take place in the group.

2. Crystal clear philosophy and work style:

If a support group has a clear philosophy, proper structure and a specific style of working, it acquires a unique identity. It also becomes stable. This enables the group to function well

and there is consistency in its manner of working. In America, there are institutions that take care of persons whose mental illness is chronic and who are highly dependent on others. In India, the situation is such that even persons with protracted mental illness come to self help groups. This poses huge challenges in running the group. Such persons constantly need other facilities and attention along with the self help group. However, though there are less facilities and conveniences, mentally ill persons do have family support. The family cares for such mentally ill persons. They are accorded due time and attention. However, we should be able to utilize the availability of family care in a better way. It is essential that family members receive training on what causes mental illness, what its manifestations are and why and how it becomes worse, how to come to terms with it and how to look after persons with mental illness.

3. Challenges in India:

America is a prosperous nation. People there are financially sound. Therefore, one can easily conclude that they can easily run institutions for the mentally ill or provide them up to date facilities. Due to their financial capability, it is possible for people there to provide monetary assistance to caregivers of persons with mental illness or such groups at least to some extent. Also, it is quite easy in America to find places for discussions or to run such groups free of charge. However, the issue here is not restricted to financial prosperity. This society, which is rich in financial terms and by way of facilities, is also rich in its wisdom. American society has the tendency to go to the root of any problem. Thus, they do not stop at setting up one group/institution but form a network of groups/institutions with common objectives. This tendency to solve problems and create a machinery for the purpose is very strong.

4. Financial support:

In India, persons with mental illness who are not employed and are totally dependent on their families, do not get much respect or recognition from relatives. Some are not even permitted to use the house phone. Since they do not have much money with them, they cannot even afford to go to a public telephone booth to phone. In America however, people who are handicapped by mental illness are provided financial assistance by the government for their maintenance.

Since caregivers in India are not financially secure, it is not easily possible for them to make substantial financial contributions to self help groups. Therefore, schools and educational bodies should come forward to provide free premises for meetings of the groups.

5. Why is India lagging behind as regards mental illness?

In the Indian philosophical tradition, there is mention of what needs to be done to maintain good mental health. Though there is no dispute about the validity of the yogasanas of Patanjali Yoga, pranayama, diet and thought control, these detailed treatises have for some reason, not reached the common man. In our society, while there are lofty ideals in our philosophy, at the same time, there are social concepts, rituals etc. which are inconsistent with this philosophy but are vexatiously ensconced in our ethos. There has been no effort to bring about changes in our philosophy appropriate to changes in social and cultural circumstances and to bring them to the masses. This is the reason for India being extremely backward as regards mental health.

6. Educational exhibitions:

In reality, modern science has proved that mental illness occurs due to changes in the brain chemicals and that this is

similar to any physical illness. However, this knowledge is not available to the common man, nor is there the enthusiasm to become informed.

In order to create this enthusiasm, scientific truths about mental illness must be reached to the people in a manner that will arouse their interest as well as be easily understandable. Exhibitions are events that always attract eager crowds of lay persons. If we can organize exhibitions using innovative concepts and ideas, they will certainly be of great use. We cannot take refuge in the excuse that our country is not prosperous like America and therefore, we cannot afford costly exhibitions like the ones there. We must think and look for resources that are in accordance with the prevailing circumstances. We will need to widen the scope of imparting education by way of exhibitions, training, new ways of running self help groups and other such options.

7. Paucity of adequate information:

The common idea of mental illness is becoming mad. Due to lack of adequate information, people generally ridicule persons with mental illness and keep away from them. Hardly anyone thinks of trying to understand them. As a result, even the family members of the person with mental illness have to bear the consequences. There are problems in finding suitable matrimonial matches for siblings as well . Nobody is prepared to provide employment to mentally ill persons. By and large, the person's social life comes to an end. The practice of denying the presence of mental illness is more serious than the problem itself. Denying the problem does not solve it. As a matter of fact, the process of seeking more information about the illness, the love of near and dear, the sympathy of friends and colleagues and other means of

support are undermined. With the right approach to mental illness, the illness alone remains to be dealt with and this helps in gradual improvement.

We must introduce and spread independent and practical ways to implement self help for those who suffer from mental illness and their caregivers. Efforts in this direction will strengthen our work and actions.

We must study and compare the experiences of S.A. and Recovery Inc. and adopt whatever is useful and effective.. We have now begun the process of reviewing the structure and objectives of our self-help group. group. We have also started introducing new processes in our mode of working. The changes we are now implementing by consulting group members and old associates are now in the final stage.

We need to adopt suitable methods and proper philosophy to run such groups, keeping in mind our vast social and cultural diversity. While doing this, we must also take into consideration the hopes and aspirations of the society. However, it will not be fair to give importance to particular faith and religion. Essentially the modus operandi of the group must be based on the psychological mould of our society.

Informative brochures on the objectives and methodology of the group and the creation of other promotional leaflets have been taken up on priority. Likewise, training sessions on the Recovery Method have also commenced. There are many books that give information on this method. These methods teach persons with mental illness to come out of their problems. I mingled and interacted with the Recovery groups for only ten days and felt that the training I had received in that period was grossly incomplete.

Just as NAMI implemented training programmes for caregivers and family members from family to family program, we too need to formulate a training programme in India on mental health for caregivers and this must be implemented in stages. In this connection we cordially welcome those who wish to render financial help or devote their time and energy for this work.

8. New ideas regarding mental illness:

My mental horizons expanded due to my participation in the NAMI conference, the various individuals and institutions I visited and interacted during my sojourn and the exhibitions I saw there. They fostered in me an independent approach to the work in the field of mental illness. I became aware of new methods of work. A few principles that resulted from this experience are as follows :

- Attention must be focused constantly on improving the utility of the self help groups.
- There should be a well-defined working system for patients's groups and caregiver's groups. If rules in this regard need to be framed, this should be done.
- A fresh decision must be taken to determine the direction of work in the field of mental illness.
- Promotional tools: The role of promotional tools in the spread of the work of American groups is remarkable. Every group keeps publishing literature on even minor issues in order to raise social awareness. We must develop promotional tools keeping these ideals in view.

9. Recovery Method:

This method enables persons with mental illness to realize which event or situation causes discomfort. The person also

understands which principles of Dr. Low are to be used at such times. It helps in understanding the connection between the symptoms of the illness and events in the person's day-to-day life. The person then learns to reflect upon which principles of Dr. Low are to be used in such situations. By comparing how one behaved and how one would have behaved had he/she not been aware of this method, the person realizes the value of the Recovery Method.

The incident has to be narrated succinctly in 5-10 minutes. Other members in the groups will put forth their viewpoints on the highlights of the event. They will refer to the principles of Dr. Low that the person used in dealing with the situation and appreciate him/her. Nobody will criticize or blame the person.

In such groups, a new member should observe how other members narrate their experiences and start narrating his/her own experience after 2-3 weeks.

By getting used to narrating one's experiences in these four stages, after a while, that particular way of speaking and behaving becomes a habit for the mentally ill person.

After the narration part ends, there is a part in the Recovery Method for questions and answers. If someone asks a question during the narration of the experience, it is possible that the narration would get interrupted and its coherence, compromised. Therefore, after everyone's narrations are over, the patients group leader can be asked some questions. By this session, patients get encouraged to voice their doubts. One discipline is followed during these meetings. Nobody is permitted to take notes. The reason for this is that the patients taking notes and can not pay proper attention to

what others are speaking.

Likewise, nobody is allowed to speak on the phone for more than five minutes between two meetings. The meetings are conducted only by persons who have experienced mental illness. Psychiatrists do not participate in these sessions.

10. Training for the family:

NAMI has a special 'Family to Family' training programme. In this, caregivers of mentally ill persons are given necessary information about the illness. NAMI has also formulated a curriculum for improving the skills of caregivers to handle issues and problems that occur frequently due to the illness. This training is given once a week for 12 weeks. This programme has been named 'Family to Family.'

In the light of the fact that the number of caregivers of persons with mental illness is very high and the number of psychiatrists is very low, this important concept of NAMI gains significance. This matter is even more important in India than in America. The number of mentally ill persons is huge. Likewise, misconceptions on mental illness are also rife. Under these circumstances, the task of setting up machinery to impart training to caregivers is indeed gargantuan!

In Conclusion...

During my visit to America, the work of various institutions there and my experience of their work and programmes were very inspiring to me. I became aware of many ways of working for persons with mental illness and their caregivers followed by a developed nation under the premise that mental health was as important as physical health.

From all these efforts, I could see the eagerness to provide factual, scientific information to mentally ill persons and their families, the desire to erase stigma from their minds and the intention to use self help groups as a supplement to medical treatment. Since America is a developed and rich nation, it is easy for them to make available substantial funds and facilities for mental health. While all this is true, I found scientific purity, organizational and professional skill apparent in their efforts, which I think is important. Though finances may be limited in India, the family support is still very strong and there is no dearth of volunteers and altruistic voluntary organizations. It is possible even in India to help patients and their families in a big way by thinking of new and less equipment-intensive ideas and programmes. If that happens, it will be a big help to patients and their families and also lighten the social burden caused by mental illness.

About Eklavya Foundation for Mental Health

Eklavya foundation for mental health was established in September 2021 by a group of dedicated and passionate volunteers who have more than 20 years of experience in the area of mental health. The main objectives of this organization are to create awareness, form self-help groups and eradicate the stigma surrounding mental illnesses.

Indian society is riddled with ignorance, misunderstanding and stigma towards mental health issues. Due to this, many patients are deprived of or delayed access to professional treatments. Moreover, patients and family members have to face a double burden... Coping with mental health symptoms as well as coping with negative attitudes of the society. Hence objective of this organization is to focus and address these issues in society by creating awareness, forming self-help groups and reducing stigma towards mental illness. This newborn organization has taken several innovative steps to achieve its objectives.

The organization currently runs separate support groups for patients and caregivers. In patients group recovery method- A method of Recovery International, USA is used. STITCH- A program to reduce stigma towards mental illness is receiving good responses among students and lay persons.

- Office -

Eklavya Foundation for Mental Health

C/o Dr. Anil Vartak, A-14, Siddhant Apartment,
312, Shaniwar Peth, Pune 411030

Dr. Anil Vartak – 9503710859 | avartak@yahoo.com



Speaking to the audience at the NAMI conference



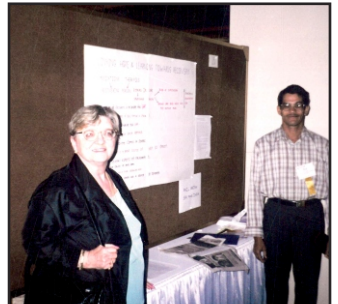
Recovery meeting



Recovery stall



The Copeland couple



With Joanne Verbanic



In the company of Recovery Inc. President Bob McIntyre



The Author

Anil Vartak is the founder of 'Ekalavya' self help group, Founder President, of Eklavya Foundation for Mental Health and was past Vice President of Schizophrenia Awareness Association. His penchant lies in using the self help method to come out of mental illness and he has led by example. Anil Vartak has done his M.A., M. Phil and Ph.D. at Pune's Gokhale Institute of Politics and Economics. He has recently retired from the post of Head of the Department of Economics at Pune's Sir Parashurambhau College. He is an office-bearer / consultant to several organizations in the field of mental health such as Sangath – Goa, Banyan – Chennai, Movement for Global Mental Health (MGMH), ESSENCE etc. Anil Vartak was invited to international conferences on mental health like in New York, Washington, Chicago in 2001 and 2005, in Kyoto, Japan in 2002, in 2004 and 2009 in Chennai and Bangalore and in 2013 in Bangkok, Thailand. His awards include 'Sangharsh Sanman' from Pune's Anita Avchat Foundation in 2005, award from Win or Win (WOW) (Chennai, 2018) and the SCARF's Media for Mental Health Award (Chennai, 2019) for his prolific literary contributions in the field of mental health.