

## PROCEEDINGS OF WFSAD 2002 CONFERENCE KYOTO: OCTOBER 9<sup>TH</sup> ONLY.

### POWER OF THE FAMILYMOVEMENT: CATALYST FOR CHANGE DAY 1-WFSAD MEMBERS' ASSEMBLY

#### WFSAD PRESIDENT'S WELCOME MESSAGE

On behalf of The World Fellowship for Schizophrenia and Allied Disorders I extend a very warm welcome to all present. It is wonderful to be back into Kyoto once again. It has been my pleasure to be able to visit Japan a number of times over the last few years.

I extend a special welcome to all our overseas visitors. Some of you will have travelled long distances to be with us. I hope that your time at this conference and in Kyoto will go well. That it will be an informative, stimulating and enjoyable experience.

Welcome to family members, mental health professionals, government officials and interested members of the wider community.

The title of this conference " Power of the Family Movement: Catalyst for Change" is a very timely one. The international family movement is beginning to be recognised for the valuable contribution it can make. As families you have tremendous power to cause change. To enable us to do this we must speak with one voice on issues that concern us. I hope that this conference will bring us closer together so that we can walk this journey as one.

This is the second time that WFSAD has jointly shared a conference with a family organisation, the last being with ENOSH in Jerusalem. WFSAD is delighted to be partners with Zenkaren for this very important occasion. We feel it is a time to share experiences, renew old friendships, and make new connections, to learn new and different ways of sharing and coping. Our hope is that it will strengthen you in your work and for the journey ahead. I would hope that whilst we attend this conference we remember that is people we wish to support and help not mental illness.

I look forward as do members of the WFSAD Board to meeting many of you over the next few days. Relax and enjoy the conference and what it has to offer.

Jim Crowe  
President WFSAD  
Kyoto 2002

#### PRESENTATIONS-9 OCTOBER, 2003

##### A CONSUMER PERSPECTIVE

**KEN UDAGAWA**

My name is Ken Udagawa. I am diagnosed with schizoaffective disorder. I am a consumer. I was hospitalised four times in a mental hospital. Each time I spent about six months in a closed ward – about two years in total. From 1991 to 1995 I was admitted four times and spent a total of two years. In all, five years in a mental hospital.

In a mental hospital there is an informed consent system. Recently I came to know that a doctor can change a prescription for a patient, but that a nurse could change a prescription as a nurse or in order to punish a patient. In Asakura Hospital doctors have given an intravenous high-nutrition drip injection to a patient and kept the patient restrained in his bed. In that hospital patients were hospitalised against their will and bound to the bed and given no water or food and kept on intravenous hyper alimentation. Patients cry and ask for water and food. This is one of the worst examples, but poor treatment is common in many Japanese mental hospitals. Many of the doctors use polypharmacy (administering of several anti-psychotic medications at the same time). I am suffering the effects of polypharmacy now. Five years ago my doctor gave me eleven kinds of different medication. At last I met a good doctor in my last hospitalisation. He reduced the medication to one new medication plus two others. She and I try to reduce the medication but it always failed. She said that I have taken too much medication for too long so my brain has withdrawal symptoms to reduce the old medication too fast. Because of the side effects I have, I go to a part time job only three times a week and the other four days I have to rest in my apartment. Most doctors continue polypharmacy of psychotropic medications. They think of medication as a bond like a chain that keeps consumers from speaking. Some doctors get angry when a patient asks about medication and some patients think is a virtue of the Japanese to ask the doctor nothing.

Well, in the mental hospital I started studying English by radio. There was no recreational program or self-help group to kill time. People do nothing but smoke while spending 3-6 months there on average. All I did was to study and improve my English and take medication. Up until about five years ago I was weak and tended to depend on my parents. Then I began to think independently when I took a trip to Los Angeles in 1997. I have worked since 1998, lived independently since 2000 and in 2002 I got married. In Japan it is very unusual for consumers to live independently. Most live with their parents or brothers or sisters till they die, when they may live on welfare or go back to the mental hospital, because community care is relatively new and social resources are poor. Before 1995 there was no idea of psychiatric disability under Japanese law. We were not considered as disabled people but only as psychiatric patient. For us to live in the community was not considered. People became weak living in the mental hospitals, and even when they returned home to their family they continued to be weak and unable to live by themselves when their families died.

I think mental health professionals and families make us weak. Consumers are beginning to be aware of this. We do not have full civil rights yet. We cannot live as a full citizen yet. But my wife and I started independent living without any support from professionals. My

wife is diagnosed with schizophrenia. She started going to a workshop but they do nothing for our independent living. High risk with no support is my life with my wife. But we two take charge of community living together and take charge of our whole two lives together.

Did you see the movie "A Beautiful Mind?" In the movie John Nash got the Nobel Prize. But it is not a movie about a person with schizophrenia getting the Nobel Prize. It is about a person with mental illness living in the community with his family and how difficult it was for them. "A Beautiful Mind" got an Academy Award in the U.S. I say your life living in the community with mental illness is worth an Academy Award, so let's share our stories

Ken Udagawa

## **ASHADEEP- A BEACON OF HOPE**

### **MUKUL CHANDRA GOSWAMI**

Twenty years back, even in my wildest dreams, I would not have imagined that one day I would be addressing a conference of the 'World Fellowship for Schizophrenia and Allied Disorders', as by profession I was a Banker. In the year 1981 when the doctor diagnosed Nilakshi, my fourteen year old sister, to be affected by schizophrenia, none in my family including 'Ashadeep, the only organization working for the rehabilitation of the mentally ill in the seven North Eastern states of India having a population of over thirty million.

I am presenting a few recollections - of both my roles as a Care Giver to my sister and later helping other families in taking care of their wards.

At the onset of Nilakshi's illness, though we had consulted a psychiatrist and she was on medication, many in our family were of the view that her abnormal behaviour was the result of some 'black magic' performed on her during the marriage of our cousin in the village. After three months when she had recovered enough to attend school again, one was not sure whether it was the effect of the medication or of the efforts of the various faith-healers 'consulted during this period. With this background, the advice of a few well-wishers on the bad effects of the medicine was enough for us to stop her medication. There was a severe relapse within seven months. Subsequently, whenever my mother wanted to try some faith-healing, I made sure that she continued receiving her medicine together with other healing processes.

**In the management of a schizophrenic patient in the family, the views of members must be respected to ensure involvement, but at the same time an enlightened member must ensure that the right treatment is administered. Now through Ashadeep I am replaying this same role in a number of families, especially amongst those from the smaller towns and villages where the access and trust on 'faith-healers' is much higher than on anti-psychotic medication.**

Following the usual route, at first seeking fast relief, we moved from one doctor to another, and finally the journey to the ultimate in our country – the National Institute of Mental Health and Neurosciences (NIMHANS), Bangalore. After undertaking a sixty four hour journey by train, running for nearly half a kilometre after Nilakshi on the totally unknown streets of Bangalore and replacing all the broken glassware of our hotel we finally entered the gates of NIMHANS with a lot of expectations. This hope quickly changed to despair, when the doctor told us that 'Schizophrenia was not curable and that we must curtail our level of expectation.

When I look back, I feel that this was the most decisive moment in the course of Nilakshi's life and our lives too. At this moment, we could have put the blame on our fate, and let things take their own course, as there were other children, other issues, other priorities to be addressed. **This path would have perhaps led to a day, when unable to bear the burden anymore, we would have looked for a 'Home', where we can dump Nilakshi for the rest of her life. This 'Home' could mean an expensive Custodial Care centre for the affluent; the streets for the poor; and in many cases a dark and unreachable room in the house which others cannot see or reach.** But we chose to continue in our efforts towards the rehabilitation process. The little know-how on mental illness gathered from my interaction with a few professionals at a personal level, helped me to insist on the renewal of our efforts in this direction.

In fact, my interest in this subject, because the need increased, led to more interaction with mental health professionals and other information sources. But here again I was fortunate in having access to the experts. Others may not be so. There are not more than 60 psychiatrists to take care of the mental health needs of the 30 million people in our region. So it is not possible for them to give much time to each patient. At Ashadeep we have tried to address this problem by educating the families on the nature and outcome of the various mental disorders. At the individual family level, this job is carried out by our counselors and family volunteers. At the macro level we use the media and public meetings. Recently, we are beginning new activities. The local organizers have drawn up very innovative programmes such as 'street dramas' and musical programs. In rural India the radio has a very wide reach.

Though I am trying hard to recollect my experiences of encounters with the **stigma** factor during my sister's illness, today I can only recount the positive aspects of the help rendered by our friends, relatives and neighbors during this traumatic period. A phone call from home at the bank that my sister has run away and is intending to leave town, compels me to leave without completing my work, but my colleagues were always there to help me out. Also I remember that at most times when I reached home, I found that the crisis has already been defused by a neighbor's son or some other friend. When Nilakshi entered the Government Guest House near our house and terrorized the guests by her aggressive behaviour, the attendants there, who were well aware of her problems, dealt with the situation and saved us from embarrassment.

The reason for this was perhaps because of the efforts of each member of our family in telling all our friends relatives, neighbours and more importantly the people with whom we come into contact regularly like the milkman, newspaper vendor and others about the true nature of Nilakshi's illness and the behavior to be expected because of it.

But at one point we also had a few thoughts of keeping Nilakshi at a long term care home, from the fear that the marriage prospects of my other two sisters would be harmed by the presence of a family member having a mental disorder. In India marriages are usually arranged by the parents and this fear is perhaps the most common reason for discrimination against a mentally ill person within the family. This problem, like earlier such problems in our family, were solved by frank disclosures.

The onset of Nilakshi's illness was at the age of fourteen, so after a few years when the positive symptoms of schizophrenia were controlled, we made a number of futile attempts to train her in some vocation, but the general pre-vocational centres did not have the necessary skills to counter the negative symptoms of her ailment. Fortunately we met a young lady who had the natural counseling skills to deal with the devastating negative symptoms of schizophrenia. Today Nilakshi is employed as a professional secretary in the school of Fine Arts run by this lady. **She had literally lost twelve years of her life to 'Schizophrenia' but is now back to leading a more normal life.**

At that time I felt that our fellow sufferers were not so fortunate, and at the beginning, my only objective was to start a Day Rehabilitation Centre, where the stress would be on pre-vocational training of the mentally disabled.

Our whole family pooled their resources to set up the first Day Care Centre for the mentally disabled in the north eastern states of our country at Guwahati in the year 1996. The premises were provided by my parents. Anjana, my wife, left her job as a teacher of sociology in a college and took over as a full-time administrator and counselor of the center. My brother in law gave the furniture and our cousins Kabin and Mandira (both suffering with cancer and Kabin also on anti-depressants) took care of the initial expenses for stationery and other fixtures. My van was used to ferry the individuals from their homes. My colleagues in the bank took turns in contributing towards the salaries of our three staff members: a psychologist, a lady attendant and a driver. Today this centre is providing counseling and training to fifty individuals at a time and has a staff strength of sixteen. It is definitely more difficult to make both ends meet now.

Starting from this Day Care Centre as a focal point, Ashadeep, today with its sheltered workshop, volunteer network, outreach programmes, family support group and awareness programs, is trying to initiate activities in the field of rehabilitation of the mentally disabled in more and more areas. Our first branch is at a village called Khetri, and in another two areas we are working with local organizations to set up such facilities.

Now I am not employed any more with the bank and am fully engaged in organizing efforts to help the mentally disabled and their families in the north east region of our country. In the smaller towns and rural areas of this region, like in other parts of India and also other developing countries, mental health facilities are either non-existent or very much limited. In this context, from my experience, I feel that all outreach programs must try to develop service facilities to achieve anything. But lack of resources and trained manpower may be a severe constraint to set up sophisticated services. So under these circumstances, small day-care centres, having at least one trained mental health worker at the beginning, and facilities for pre-vocational training and a sheltered workshop would perhaps be a most effective concept in initiating activities in new areas.

Mukul Chandra Goswami,  
'Ashadeep',  
Islampur Road, Gandhi Basti,  
Guwahati – 781003, Assam, India.  
Ph-91-361-523837 / 91-361-666794  
e-mail – [ashadeep@onlysmart.com](mailto:ashadeep@onlysmart.com)

## **SELF-HELP FAMILY SUPPORT GROUP IN GOA** **NAMDEV GAWAS**

### **STATISTICS OF GOA**

Total Area	3702 sq.k.m.
Population	1.3 million
30 psychiatrists	1 million population
156.2 psychiatric beds	1 million population
Goa medical college every year produces	70 graduates 2 years hence 100
Literacy rate	78%
Tourism major industry	1.3 million per year
Sex ratio	967 females per 1000 males
Birth rate	14.7 per thousand
Death rate	7.8 per thousand
Density of population	316 per sq. k.m.
No. of districts	2

Source: 1. Statistical Pocket Book of Goa printed at the Government Printing House.  
2. World Health Report 2001.3. I P H B. ( Institute of Psychiatry and Human Behaviour)

### **THE LOCAL SITUATION**

Self-help family support groups, a new concept in Goa, are increasingly emerging as one of the most effective treatments for mental disorders and addictions. Family work, when effectively practiced, has the capacity for tackling cases ranging from

alcoholism (very common in Goa) to Schizophrenia to drug addiction and is also useful in the rehabilitation of women who have been the victims of family quarrels, rapes and such mental trauma. Goa has a highly institutionalized approach to mental health care, but is lacking in community care and has no rehabilitation centres, no strong NGO's, despite being one of the states with the highest number of psychiatrists in the country.

A factor which contributes in large measure to the mental problems of people in Goa is alcohol. This has a huge impact on family members. Alcoholism in Goa is rife as compared to the other states. Drug addiction is also prevalent amongst the children of higher income groups. Pedophilia (child sex) cases were also reported where helpless children under the care of the orphanage were sexually exploited.

In Goa, the suicide rate is very high. Recently a suicide helpline has been started by the Goa Psychiatric Society. Child helpline was also started at 'Sangath' Centre at Porvorim-Goa.

### **FAMILY SUPPORT MOVEMENT**

The family support organization 'Adhar' has been recently started under the aegis of Goa Psychiatric Society. At present, we have nearly 30 family members registered. We conduct monthly meetings and the members usually tell of their experiences. But the aim is to go beyond this aspect and to serve as a well organized self-help family organization. At present, we do not have our own premises but we will have to start from where we are. It is heartening to hear that more and more persons want to know more about the movement and seek information. For this reason we recently organized a one-day workshop, sponsored by the Goa Psychiatric Society. 'Adhar' is now in the final stages of registration under the Society's Act of 1860.

National mental health programs are in development. Integration of mental health with primary health moves along. In fact, one good thing about Goa is that one will find a sub-centre in the remotest corner with free access to medical practitioners. Nevertheless we need more persons with skills in mental health capita. Psychiatrist alone cannot solve this problem. Shifting the paradigm to the trained local people is a must.

Goa can become an ideal state for mental health, but for this political will and will of the people is needed.

Looking our need and the existing machinery, we have one Institute of Psychiatry and Human Behaviour (I.P.H.B) at Bambolim, where help is available to patients. Psychiatrists practise privately in the major cities, but the magnitude of the problem is overwhelming. We find sick persons on city and village roads and in homes where they are kept well camouflaged because of the fear of social stigma.

### **PLIGHT OF AFFECTED FAMILIES AND PATIENTS**

Families are in a difficult position. From one side they are subjected to unfounded criticism making them responsible for the change in the mental condition of their family member and from the other side the patient is not co-operative because he is unaware of the changes occurring in him.

In the absence of adequately prepared staff, the family is a victim in the hands of unscrupulous, so called Ghadis, disticars, witchcraft, Bhutas or spirits, scoundrels and hypocrites, who exploit the whole situation in the name of God, for their own benefit.

Patients improve under medical care, provided it is adequate. Society at large has to help patients with rehabilitation. But he continues to be a lonely man living in a world of his own creation. In a discussion, he is adamant about his views and sticks firmly to his beliefs, unable to compromise and unable to understand others' views: his grandiose ideas can lead him and his family in difficulties, the medicine under which he has improved has to be taken for an indefinite period to avoid relapses.

Even then, he is unable to maintain the same relationship with his attending doctors. He likes them initially but ends with thinking that they want him always handicapped and depending on them. Sometimes he makes them responsible for his condition. The case of Portuguese Nobel prize winner neurologist Dr. Egas Moniz is known. He was fired on by a person with schizophrenia while he was paying his usual visit in a psychiatric ward. Dr. Moniz miraculously escaped and it was found in the diary of the patient, that he wanted to kill Dr. Moniz because the patient always thought that Dr. Moniz was interested in keeping him ill. The episode is narrated beautifully in the book *Confidences of one Scientist* by Dr. Moniz.

People with abnormal behaviour need to relearn skills and this is where para-medical staff, social service clubs and self-help family support can help to restore the patient. Unexpectedly in the course of time, whether as a result of treatment or not, the patient starts to improve. He repairs his broken life and society around must see this change with sympathy. The family continues to help but the environmental help has to come as well.

The author of this line has passed by similar experiences in his family. Experience is a great teacher. Unless one experiences this problem on his own skin, he is unable to understand what it is to pass the days with people with abnormal behaviour.

In Goa, many poor families have grown up girls, educated girls with college degrees, working-class girls who sacrifice their life for family maintenance. If they marry a well-to-do boy who for some period, for some reason was behaving abnormally, will not they improve their own life? Will it not restore to society one boy in seclusion to his benefit? Will they not help his and her family's condition for the well-being of all concerned and society? The same case is applicable when it comes to a boy.

Recently, I saw the Oscar award winning film ' Beautiful Mind' .The principal actor who represents the role of a mentally ill patient, is something unforgettable!

Let us take a lead in improving the situation in Goa without waiting for the government to come into the picture.

### **SOME SUGGESTIONS:**

Humanizing the mental health facilities to decrease stigma.

Integrating mental health with public health.

Having a wide range of community care services.

Developing support groups for the families of patients.

Massive public education to educate the public on this matter.

Emphasis on working with families

Initiation of volunteers.

Mobilization of funds and resources.  
Formation of core group.  
Paramedical staff, which should be asked to visit families in distress.  
Monitoring and Evaluation Technique.  
Mental Health Policy outlined by GPS  
Empowerment of carers etc.

### **IN CONCLUSION**

I have come here with great enthusiasm to participate in this fifth biennial conference on the Power of the Family Movement: Catalyst for change. I know that with the presentations and interaction I will get many ideas and suggestions and will be recharged to return and work with the family movement group back in Goa.

By Namdev M. Gawas  
Secretary 'Adhar'  
C/o Pandarinath Shirodkar  
Opposite I.T.I., Peddem-Mapusa-Goa.India.  
E-mail: gcacpg @ goatelecom.com

Paiaf is next

### **A SOUTH AFRICAN PERSPECTIVED**

#### **JESSIE MACINTOSH**

I am Jess Mackintosh and come from Cape Town, South Africa. I feel very privileged to be able to attend this conference and thank the World Fellowship for Schizophrenia and Allied Disorders for their very kind and generous invitation. It feels like a dream to have the opportunity to meet and hear so many people from all over the world speak on a subject that I feel so passionate about. I represent Cape Support for Mental Health, our support group in Cape Town as well as Com Care Trust and Hope House Trust, both of which provide community housing for adults suffering from a mental illness. Sadly, Mr Graham Louw of Cape Town who would have represented these organisations is unable to do so due to family ill health. He has been my mentor, colleague and friend for many years.

I speak today as a mother. South Africa has a population of approximately 44 million of whom approximately 4 800 million are referred to as white. The political history of our country provided first world facilities for the privileged white community to the detriment of the predominantly black community. Today we have political freedom for all. We have worked hard through forgiveness and reconciliation. In the field of Mental Illness we are trying to integrate the African traditional healers with western medical doctors. This is not easy. We often have communication problems as there are 11 spoken languages.

In addition our facilities are totally inadequate due to a downscaling of the hospitals as well as a massive shift of our black population from the rural areas into the urban areas. Black traditional family care has been eroded and the hospitals have to cope with more and more cases of severe mental illness such as schizophrenia. The authentic traditional healers have success in the less severe cases of mental illness but referrals for the more severe cases are usually too late, putting even more stress on the overpopulated hospitals. After discharge, the relapse is very high, often due to cultural beliefs and superstitions. We are trying desperately to establish support groups in our black townships to foster a better understanding of the illness and to provide support for the families. We are establishing psychosocial groups for the consumers and on a larger scale intensive support in the form of group homes.

I have three children. My youngest daughter Lindsay suffers from schizophrenia. She has now been ill for 12 years. She was a bright student, qualifying in the field of physiotherapy and an excellent athlete. A lovely girl with the world at her fingertips.

When she became ill my family were devastated. We knew nothing about mental illness – in fact she knew far more about her illness because of her medical background. My salvation was Cape Support for Mental Health, a support group that was started 20 years ago by 6 families. At that time no support group existed in SA. I was later to become chairperson of Cape Support for Mental Health. Today Heather Mckenzie has the chair, a vibrant and enthusiastic mother. We have a membership of over 100 members and meet once a month either offering expert speakers on different subjects, or we break up into small group and share our experiences and anxieties. We have an active and up to date library, encouraging members to learn more about mental illness. We regularly give radio interviews, and address private and community gatherings. We take a strong stance against negative reporting and advertising and fight the stigma associated with mental illness. We are in the process of establishing a website, the first support group to do so in South Africa. Most importantly we try and help our members to be positive about the improvements in mental care and medication and to look forward to a better life for their families. We are proud of what we have achieved. My very active involvement in the Support group gave me the confidence and energy to move onto my other involvement and real passion, group housing. I firmly believe that sufferers should be allowed the opportunity of living in a home where they are treated with respect and dignity, a home where they can be given a level of independence.

Three and a half years ago my daughter Lindsay became very ill and was hospitalized for over 15 months. It was a very traumatic period as she was contained in a psychiatric hospital for over a year in a safe ward where she showed no improvement. During the latter part of this period it was suggested that she be given a companion, as her only interaction to date was with the severely ill. The Doctors and social workers were overworked and seldom had more than a few minutes to spend with her. Permission was obtained from the Minister of Health as this had never been requested before and soon after Zainab was employed as her daytime companion. Lindsay's condition improved almost immediately and soon she and Zainab would be seen sitting out side on the benches, talking away and often crocheting. This was to change her life! In teaching Lindsay to crochet, she was also being taught a tool to help her with the voices intruding in her life. Her condition steadily improved and I started looking for a group home where she could be cared for on discharge. I became acutely aware of the fact that no 24 hour supervised care facility existed in Cape Town. Fifteen years earlier Comcare Trust under the leadership of Graham Louw, had been formed to provide supported accommodation for young adults suffering from mental illness. Today, Comcare provide accommodation for over 40 people, some in group homes with part time care, and others in flats, where they live almost independently. However, Lindsay needed 24-hour supervision and there was no

suitable facility that provided for these needs. There was no choice but to provide this accommodation! Although the government provides a subsidy for those suffering from mental illness, this is not enough to cover the costs of running, let alone establishing community homes.

I committed myself to establishing a home which would allow Lindsay and others like her to fulfill their maximum potential. Hope House Trust was formed, and two months ago, with much pride and excitement the first Hope House was opened, providing accommodation where people with severe mental illness can live with 24 hour supervision. Hope House also provides structured living and daily occupational therapy. The latter I insist on as this does provide sufferers with a tool to cope with their delusions and hallucinations, and therefore helps maintain stability. I can't explain the thrill it gives me to walk into the house and find the residents gathered around the table, laughing and busy, secure in their home. It has been a wonderful and rewarding experience and we are determined that this will be the first of many Hope Houses, stretching around the country. Our work has just started. We still have a shortfall on our payment of Hope House and we will continue to fundraise in order to pay for the care of our residents as well as working towards other Hope Houses. Every rand spent on capital infrastructure has been raised through donations and fundraising activities. This has been extremely difficult as there are so many charitable causes in need of funding.

It has been a long and hard journey for me. I still feel heartbroken when I see the hospital wards filled with young adults suffering from mental illness, I still feel the pain of the new parents who have just heard their children's diagnosis, but I continue to marvel at the dedication of the staff at the hospitals working under difficult conditions, and the generosity of those wanting to help.

Last year at the SA Conference a vibrant Sotho psychiatric nurse, Cisebo Sefoka, from Limpopo, far up north, told her story. A mother herself of a young son suffering from schizophrenia she has started a support-group. There are already ten families involved. She needs as much help as possible. I admire her courage in starting this group and our hope is to assist her as much as possible. At this stage we cannot help her financially but can assist her in the structure of the support group and how to access funds.

I can confidently say that, despite the enormous problems facing South Africa, there is a glimmer of light at the end of the tunnel. South Africa has a strength, a strength of spirit and commitment and although we do not have first world hospitals; nor do we have sufficient resources for our needs, and there are not enough doctors interested in investing in psychiatry, non the less a greater awareness of, and concern for the mentally ill has developed. Fifteen years ago, my daughter Lindsay would have lived her life in a mental institution. Today, with the improvement of medication and the facility of Hope House, she is able to live her life with dignity in a secure and comfortable group home. It is our dream to make this available to all sufferers.

There is a lot still to be done but I feel passionately that it is definitely worth battling on. I often remind myself of the last paragraph of Nelson Mandela's book.

*I have walked the long road to freedom. I have tried not to falter; I have made missteps along the way, but I have discovered the secret that after climbing a great hill, one only finds that there are many more hills to climb. I have taken a moment to rest, to steal a view of the glorious vista that surrounds me, to look back on the distance I have come. But I can rest only a moment, for with freedom comes responsibilities, and I dare not linger, for my long walk is not yet ended.*

Jessie Mackintosh, Comcare Turst,, Cape Town, South Africa.

Erkin Toktosunov, Kyrgyz Republic – [We have asked him by email 6-5-03 if this presentation is on computer and could be sent.](#)

[Helen Dabu. Philippines. Any text?? Have it on the tape.](#)

Mr. Egami – [nothing from him.](#)