

Bulletin 13(3), October 2001, p1

President's Report:

SPANISH ASSOCIATION EXTENDS TO ALL REGIONS

President Riccardo Guinea will report on the excellent meeting and organizational developments I was delighted to attend in Madrid on October 24-26 2001. A full report will appear in the next issue of the *Bulletin*, as we begin publication in all three of WAPR's official languages. We look forward to returning to Spain for the WAPR cosponsored ARAPDIS conference in May in Barcelona.

I continued to the World Association for Social Psychiatry World Congress in Agra, where our Indian colleagues discussed both the WFSAD meeting reported below and the Erwadi tragedy. So much has happened since the last issue that choosing the focus has been very difficult, especially with the Board's suggestion that the *Bulletin* seek less density. Yet we go back to small type for two reports from India because they should be considered together. WAPR is committed to working closely with WFSAD and sees this report as a prototype for what can and should be done in any country. We in New York City are very grateful for the many offers of support from WAPR all over the world and will discuss the World Trade Center tragedy in the next issue.

First National Meeting Of Caregivers of People with Major Mental illness - Chennai (Madras), May 25 - 26. 2001

Report prepared by Dr. Radha Shankar, Organizing Secretary and Vice President WAPR and Member of the Board WFSAD

Executive Summary

The World Fellowship for Schizophrenia and Allied Disorders (WFSAD) is a not-for-profit voluntary organization with the primary mission of promoting the development and maintenance of family support organizations. It is hoped that families will benefit from the process of support and self-help, and serve as a catalyst for the provision of better quality of care and quality of treatment, both medical and social, to persons with schizophrenia and allied disorders.

The Chennai initiative (which was facilitated by colleagues from all over India who identified and encouraged caregivers to participate) brought together for the first time, family members from all across India in a **Stand-alone**

meeting.

The focus of the two-day deliberations was on the role of caregivers and family organizations in care provision, working with professionals to improve services, networking, lobbying, and collective action by families in the reduction of stigma. Established family organizations, family members affiliated with mental health NGO'S and hospitals, and interested caregivers attending in their individual capacity, participated in the two day meeting. The profile of the caregivers was urban, educated and middle class, with a mixture of siblings, parents and spouses.

Families were appreciative that the professional establishment was paying attention to their needs, and spoke of the emotional and logistical challenges in providing care to their relative. To many of the participants, the caregiver groups represented a forum for emotional support as well as acquisition of information, knowledge and skills for better patient management. Caregiver groups reported that they were involved in collective efforts to support tertiary mental health services, and in the removal of stigma. The resonant message of the meeting was that while caregivers could work along with professionals to meet the challenges of India's limited mental health infrastructure, they needed guidance and empathy from professionals to manage the difficulties in their personal lives, and that as a collective, they need the active support, encouragement and assistance (with material and other tangible resources from the mental health establishment) to mobilize and sustain family groups.

This meeting has drawn attention to the potential of families to make the transition from passive carers to proactive carers, from stigma sufferers to stigma busters, from passive recipients of services to active collaborators. ***It is imperative that professionals should take on a catalytic and facilitatory role and reorient themselves in their interactions with families to be able to actualize this potential.*** However, given the fact that family groups are in their infancy and are almost exclusively middle class and urban in their constituents, at this juncture, it may be premature to comment on the nationwide impact and sustainability of this movement.

Inaugural ceremony

The Honorary Secretary of the IPS was requested to speak on "**Person's with Disability Act: Implications for people with mental illness and their families.**" The President Elect of the IPS delivered an address titled "**Role of the Family: Challenges in the Days to Come.**"

The video film "A Family for Families," which was commissioned by the World Health Organization to commemorate World Health Day 2001, was screened during the inaugural function.

Demography of caregivers

Participants were urban, educated (English speaking), and middle class with a mixture of parents and siblings. As is to be expected, the majority of parents were older than sixty years, and siblings were in the age range of 30-40.

SESSION ONE: GETTING TO KNOW EACH OTHER

Self-introduction by participants: This session included presentations by family groups, representatives of mental health institutions, and individuals who had been encouraged by psychiatrists to attend the meeting. *(Please note that these three groupings have been made **only** to facilitate an understanding of the family movement, and that the formation of many "independent" family organizations has been catalyzed by professionals who may continue to be associated with these organizations in an advisory capacity.)*

Presentations by independent caregiver organizations: Amend, Bangalore; Aasha, Chennai; Ashadeep,

Guhawati; Family Fellowship Society, Bangalore; Kiran, Mumbai; Maitri, Mumbai; Margadarshi, Bangalore; Maargadeepthi, Palghat; Rashmi, Delhi; Schizophrenia Awareness Association (Ekalavya, Pune); Subitcham; Madurai. Each group detailed a range of activities which were both impressive and innovative. These presentations brought into focus two issues:

Rehabilitation and aftercare services need to be developed through systemic and policy changes in the formal health and welfare sector.

However, approaches outside the formal system should also be encouraged. This will help in the identification of existing community resources, and promote their optimal utilization.

It was possible to identify three main strands of activities undertaken by family groups:

Self-help: *Activities initiated by caregivers themselves to enhance mastery over their difficult environment:* The concept of self-help was broadly defined, and encompasses a wide range of activities initiated primarily by the caregivers themselves. The rationale behind these activities is to enhance coping and mastery over the difficult situations that families and patients encounter. These activities are testimony to the creativity and commitment of family groups, who are not relying solely on the formal mental health system to provide answers to their problems, and included the following:

Equipping members and non-members of the group with knowledge and skills to manage their ill relative: This is arranged through interactive meetings with Mental Health professionals in non-clinical settings, and disseminating illness related information and literature. Family groups organize discussions, role-plays and sharing of personal experiences to improve the knowledge and skills of caregivers. Some organizations utilize the "Free Advertisements service " provided in the media to publicize these meetings. One carer support group publishes a quarterly newsletter in English.

Providing emotional support through the creation of informal networks for both the patients and caregivers: Family groups organize recreation and leisure activities for their ill relatives, and one family organization uses this network to identify supported job opportunities for patients.

Provision of information: Information is provided (by telephone, mail and personal contact) on issues related to treatment, rehabilitation, aftercare and residential facilities.

Arranging short-term respite care for patients: Respite care in a safe environment (lasting from 7 -10 days) is arranged at reasonable rates by family groups. This is to allow relatives to attend to urgent personal or work related commitments.

Assisting in crisis: Crisis care is facilitated by family organizations through networking with psychiatrists in the private sector. Sensitization programs for the police (to help them understand their obligations to patients and families under the Mental Health Act 1987) has been an innovative program of some of the caregiver groups.

Providing structured day activities for patients: Two caregiver organizations were involved in running day centers, which offered occupational therapy and prevocational training. One of these organizations manages a sheltered workshop for clientele who have been trained at the local Vocational Rehabilitation center (which imparts training to the physically disabled). The products from this center have won prizes in local trade exhibitions.

Managing residential centers: A few family organizations are involved in the administration of residential facilities, and some groups mentioned that they intended to start half way homes.

Caregiver involvement in outreach programs: Involvement in outreach programs includes conducting mental health camps in areas, which are poorly served by the health system. Family members serve as volunteers and coordinators in these camps, which are aimed at detecting major mental illness.

Linking with religious social service organizations: The provision of emotional and social support to families and patients through linkages with religious organizations is an innovative approach used by some family organizations. This group has also arranged for the social service organization to "adopt" two needy families who have mentally ill individuals, and provide them with financial support and employment opportunities.

Sensitization workshops for siblings of people with mental illness: This important program is aimed at enhancing the involvement of siblings of people with mental illness, and a few groups are active in this area.

Information booths in state hospitals: One family organization intends setting up an information booth in a large state hospital and has initiated discussions with state mental authorities on the subject.

Creating awareness and fighting stigma: *includes activities which inform the public about issues related to the early detection and management of mental illness. The process of information dissemination may help to remove negative stereotypes about mental illness and reduce stigma.*

Organizing public meetings: Most family groups are active in this area, and it is heartening to know that they have received excellent cooperation from professionals in organizing public meetings.

Participation in rallies: Family groups participate in rallies involving people with physical and mental disabilities. A quarterly newsletter published by a family group is mailed to organizations dealing with the physically disabled. This has helped to promote linkages and cooperation with these agencies, and has resulted in job opportunities for people with psychiatric disabilities.

Utilization of mass media: Family groups have successfully utilized the importance of radio as a medium to create awareness, especially in rural areas. Caregivers also participate in television programs, and have been interviewed in the print media.

Sensitization of service and philanthropic organizations: Family groups interact with service organizations like Rotary and Lions to spread awareness messages. This has also resulted in job opportunities for patients. The State Government of Karnataka has sanctioned a grant to a Bangalore-based carer group for spreading awareness.

Drawing public attention to mental health events: Family groups run special awareness programs during events like World Health Day, Mental Health week and World Disabled Day and capitalize on the media attention that is available during such events.

Protests against distorted portrayal in the media: An effective approach to tackling stigma has been writing to the local Censor Board about the distorted portrayal of the mentally ill in the electronic media and cinema. This family group has not only received a positive response from the Censor Board, but two producers subsequently wrote to this organization, seeking their advice on matters relating to mental illness.

Awareness about census enumeration: The 2001 census was significant because it allowed for people with disabilities (including psychiatric disabilities) to be enumerated as a distinct category. One of the family groups collaborated actively with the State Government to ensure cooperation by families and patients. This was done by highlighting the importance of this census enumeration for policy formulation and program planning.

Lobbying: (includes those activities aimed at enhancing treatment and aftercare facilities for the mentally ill thru policy and legislative changes): Simple but effective lobbying activities emerged during the presentations.

CGHS issues medication for longer periods: A Delhi-based family organization has lobbied the Central Government Health Service (CGHS) to ensure that psychiatric medication is issued for longer periods. This has reduced the hardship for elderly caregivers.

Caregivers participate in discussions on the People with Disabilities Act (PWD Act): Family groups have been active in lobbying for amendments to the PWD Act. Representatives of these groups have participated in meetings convened by the State Departments of Social Justice and Empowerment to discuss the creation of the statutory bodies to oversee the implementation of the Act. Representatives of Bangalore-based groups have also been made members of the State Coordination Committee, and serve as permanent invitees to all meetings on mental illness in the Office of the State Commissioner for Disability.

Social audit of half way homes: Lobbying by Bangalore-based groups has resulted in the creation of social audit teams to study issues related to care provision in half way homes. These teams also include family members. The State Government has also acknowledged the request of this family group to revive inspection teams and the Mental Health Authority under the 1987 Act.

Family organization obtains grant from the Central Ministry: Ashadeep, a Guhawati based family organization has obtained a grant from the Central Ministry of Social Justice and Empowerment under the scheme of assistance to Non Governmental Organizations. The representative of this group made an impressive presentation on the lobbying efforts and the perseverance required to obtain this grant.

Presentation made by family members deputed by professionally managed organizations: Antara, Kolkata; Banyan, Chennai; Christian Medical College, Vellore; Institute of Mental Health, Hyderabad; Friends for the Needy, Chennai; Father Mullers College, and Hospital, Mangalore; Navajeevan , Chennai; Paripurnata, Kolkata; Richmond Fellowship Society, Bangalore; Samaritans, Mumbai; Sanjeevini, Delhi; SCARF, Chennai; Sahanaya, Colombo.

Several Mental Health NGO'S deputed representatives to attend the caregivers meeting. Family members are called upon to participate in the activities of professionally managed organizations in the following two areas:

Family education: Families receive regular feedback about the progress of their ill relative, either in individual or group sessions this helps to enhance the knowledge and skills of the family member to optimize recovery of their patient.

Volunteering activity by families: Family carers assist professionals in the running of residential facilities and day centers by serving on committees or volunteering to supervise some of the activities in these settings. Carers also assist in organizing recreation and leisure activities for clients attending day centers and participate in fund raising and awareness creation.

Presentations made by family members attending in their individual capacity

These individuals made simple and heartwarming presentations about the challenges they had faced in attempting to understand the illness, and also provide care for their ill relative. They stressed that the while the concept of carer support groups and family organizations was new to them, they had come to this meeting in a spirit of learning, and sharing.

Presentation by Dr. Radha Shankar: The story of the international family movement: What does this mean to us?

The presentation included the following main themes:

The evolution of the family movement in the West, and the growing importance of family education and intervention.

The lobbying efforts by western families to ensure budgetary allocations for family education, as well as to develop a range of Community Mental Health support systems.

A brief introduction to the main activities of family groups across the world.

The macro realities of India as a developing country, and the consequent limitations of the Indian mental health system.

The challenges confronting Indian professionals, Indian patients and their families. The question "**what needs to be done**" was thrown open for discussion in the group meetings.

SESSION TWO: PANEL DISCUSSION: Voluntary work by families: An appraisal of the challenges, difficulties and satisfaction. Four panelists drawn for the delegates presented their views on this topic. In addition there was active participation from the floor.

The challenges and satisfaction of doing voluntary work by family members.

Suffering: the great motivator: Many family members experienced difficulties in identifying, accessing and getting treatment for their loved one, and also making the psychological adjustments. This suffering was sufficient motivation to join family groups, and help mitigate the problems of other family members.

Reducing isolation through sharing: Several caregivers mentioned that it was a relief to join family groups and know that they were not alone and isolated. And after having experienced this support, they were keen to assist in ending the isolation of other families.

Gratification provided by community service: The calling of a higher order.

Satisfaction through emulating a role model: The role model provided by a Senior Mental Health professional was the inspiration for one caregiver to get involved in carer support activities.

Utilizing time meaningfully -- a source of fulfillment: Another senior citizen remarked that he had time on his hands, and involvement in carer and patient support was a fulfilling way of spending his time.

Difficulties experienced in running carer support groups.

The panelists and delegates identified the following difficulties faced both by individual caregivers, and family organizations that were involved in carer support activities:

1. **Financial:** All family groups spoke of the uphill task they faced in raising funds to sustain their activities. Sources of funding included donations, fund raising events and membership fees. The creation of a corpus fund to provide a steady income remains a daunting task. The Ministry of Social Justice and Empowerment and the Handicap Finance Corporation provide grants and loans, but the experience of the Guhawati-based family organization suggested that obtaining this grant was not an easy task. The representative of this group succinctly highlighted the fact that the inspection team from the Ministry was insistent on doing assessment of IQ for their mentally ill clientele. It is therefore clear, that even at the highest levels of policy and program implementation, the differences between mental retardation and disability due to mental illness are poorly understood.

The panelists suggested that occupational rehabilitation work could generate money if the products were economically and commercially viable, but many family groups lack the expertise in this area.

2. **Inconsistent support from mental health professionals:** Some organizations received regular support from professionals by way of guidance and access to resources. Many family groups acknowledged the time and effort of enthusiastic professionals who participated in role-plays and dialogue sessions for the benefit of family members. However, most family groups observed that professionals (in spite of repeated requests) did not encourage families to join family groups. The reasons for this are not clear. Families suffer from lack of time and multiple responsibilities. Younger caregivers have to balance several responsibilities in their personal and professional lives, which reduces their time commitment to family groups. Senior citizens do not face the constraints of time, but often have limited mobility. However, to both groups, the care giving role itself is often emotionally taxing. All family groups opined that it was necessary to have at least one paid staff member to coordinate and take on the physically demanding tasks.

3. **Difficulties in attracting a large number of committed workers:** Many of the delegates identified three distinct groups of families who make contact with family organizations: (a) families who are seeking solutions for their pressing personal situations, and who drop out after attending a few sessions; (b) natural caregivers who are initially attracted to family groups in order to obtain assistance for themselves or their relative. Thereafter, these individuals recognize that group activities facilitate the fulfillment of two distinct needs. Firstly, the need for affiliation with people in similar situations; and secondly, the desire to do community service. These family members generally become active members of family groups. However, their involvement is often constrained by their obligations to family and the process of wage earning; (c) family members who are completely committed to the movement, and who have a realistic understanding of both micro and macro level issues in India. It was recognized that this total and focused involvement was often limited to only a few members in each group.

SESSION THREE: GROUP DISCUSSION "What are our problems, and what can we as family members do to solve them"

1. **Lack of information about mental illness leading to a delay in treatment:** The lack of information about mental illness, and the failure to receive adequate guidance on treatment options, often contributes to a delay in the initiation of treatment. Sometimes, professionals unfairly blame families for this delay, and they need to recognize that many factors, including stigma, were contributory.

2. **Lack of knowledge about the illness and the skills to handle their patients:** The lack of regular guidance from professionals, especially on managing complex situations involving the patient was perceived as a major problem.

3. **The paucity of aftercare facilities, specifically day centers and vocational training centers:** This was an issue of major concern to families and family groups who supported caregivers of patients with a long duration of illness, or those who had developed the illness at adolescence. Such individuals are not able to continue their education, or may fail to acquire job-related skills. In urban areas, this was a major source of stress. Families felt that it was

necessary to provide long-term occupational support to these individuals so as to promote recovery and prevent relapses. .

4. **Absence of job opportunities that are accommodative of the disability:** Caregivers felt that some patients worked sporadically, because the work environment expected them to perform like individuals who were not experiencing any stress.
5. **Absence of medical insurance for mental illness:** This was perceived as a great problem, because a single medium term hospitalization could wipe out the savings of a middle class family
6. **Financial problems:** Families identified two sets of problems as the source of financial difficulties: 1) having to purchase medication for a long-term illness. 2) having to cope with a patient who may not be economically productive on a regular basis.
7. **Limited guidance from general practitioners:** Family groups and individual families felt that General Practitioners had very little knowledge about mental illness, and were not able to provide adequate guidance to them on any matters regarding their patient .
8. **"When I am gone":** Caregivers also raised issues related to the care and security of their relative after their lifetime, and wanted to know what could be done to safeguard the interests of their patient.

What do families want from the mental health system?

1. **Training of general practitioners:** General practitioners (GP's) should be trained in early detection of mental illness and appropriate referral guidelines should be established brochures and pamphlets should be developed to educate GP's. Psychiatry should be given due importance in the curriculum for the basic medical degree so that all medical practitioners would have sufficient knowledge to detect early mental illness and initiate treatment.
2. **Guidance from professionals:** Families want detailed guidance from professionals on managing the illness, and both individual and group discussions should be conducted. Patients also should be "counseled" by professionals.
3. **An understanding of the emotional strain of care giving:** Families want professionals to develop a more sympathetic and listening approach. They should view the patient and the family not merely as a diagnosis or a problem, but as people who are struggling to come to terms with an illness about which they had no prior understanding or knowledge.
4. **A range of community services:** Families want the range of community services to include treatment facilities, day centers and vocational training centers with adequate intersectoral coordination and linkages.

It was suggested that Vocational Rehabilitation Centers (VRC) that have been set up to help the physically disabled should provide opportunities for the training of people with psychiatric disability. In India, the few day care facilities in existence also serve as vocational training facilities. These day care centers should receive training, production and marketing guidance from VRC'S. Families also wanted more information on micro credit schemes and guidance to take up activities that could lead to economic self-reliance. The experience of Ashadeep of Guhawati in this regard could be taken as an example.

5. **State sponsored awareness campaigns:** Family groups are seeking government collaboration for the conduct of mass media campaigns to dispel myths and misconceptions attached to mental illness. Their contention is that public money has been allocated for other awareness campaigns (like AIDS) and it should be used for mental illness

as well.

6. Creation of statutory bodies to oversee the Persons With Disabilities Act: This act should be implemented without delay, and family members should be represented in all statutory bodies, and their views should be elicited on future discussions on amendments.

7. Support the creation of family groups and help sustain their activities: Families need active encouragement and guidance from professionals to start family groups. Many families do not realize that they can make small and meaningful contributions, and would benefit from professional guidance to realize this potential. Existing family groups need ongoing support from professionals to sustain their activities. Government aid, as well as tax concessions, must extend grants for start-up costs.

What are family groups willing to do?

Work with mental health professionals in tertiary care services: Family groups are willing to take on volunteering roles in the following areas. a) participate in the activities of day care centers and half way homes in conjunction with professionals; b) help to market products made in day centers; c) help identify job opportunities for clients in the community; d) explore the possibility of work cooperatives, which could provide supported employment for patients.

Facilitate the acquisition of knowledge and skills by families: Carer support groups are willing to work with professionals to help families obtain illness related knowledge and skills. This is through learning and sharing from both professionals and other families. Family support groups are also willing to work with professionals in developing a range of educational material to meet the needs of diverse caregivers. Most family groups acknowledge that they have the primary role in caring for their patients, but they would need active support from professionals.

Provide support to caregivers and patients: In urban areas, family support groups define for themselves, the role of providing emotional support to other caregivers.

Create awareness and fight stigma: Carer groups have identified the creation of awareness as one of their major activities. They propose to do this through their newsletters, and the use of electronic and print media. The support of the mental health system is important in this initiative, and it would help. If professionals imparted training to families on these matters. Families also realize that they have major role to play in fighting stigma and they plan to do this by (a) by providing accurate and factual information to the public and media; (b) protest against inaccurate and stigmatizing depiction of the mentally ill; (c) acknowledge, with dignity and respect, the presence of the disabled person in their own family.

Spread the message of self-help: As the concept of self-help is relatively new, family groups have a role in educating families about the realities of the Indian situation and mobilizing families towards self-help.

Lobbying: Lobbying has been identified as one of the major activities of family groups. The following issues need lobbying at national, regional and local levels: a) to secure the rights and privileges of people with mental illness through legislative means; b) to obtain greater budgetary allocation for development of health and welfare services that are necessary to promote social reintegration of people with mental illness. The focus will be to ensure both equity and access to services, irrespective of the individual's capacity to pay for the service; c) to define through a consensus process, the minimum standards of care in facilities, which provide treatment, rehabilitation, and residential care for people with mental illness. Also to set up mechanisms for monitoring and redressal; d) to obtain medical insurance coverage for the mentally ill and for mental illness; e) obtaining bus passes or subsidized travel for patient attending day centers or vocational training programs; f) to sensitize policy makers about issues related to mental illness.

SESSION FOUR: Where do we go from here?

All delegates opined that this meeting was only a starting point, and that regular follow-up must be held in order to build up a family movement in India

Networking and exchange of information amongst the delegates was agreed upon. Caregivers representing informal groups mentioned that they would aim to get their groups registered as formal entities.

Caregivers attending in their individual capacity hoped to start small self-help groups, but needed the guidance and support of local professionals.

Caregivers were apprised of the ongoing attempts to create a national federation of caregivers to undertake lobbying at the national level, and it was decided to form an ad hoc committee to pursue this subject more vigorously. It was tentatively suggested that the ad hoc committee should meet in New Delhi in about six months.

Valedictory Function: The program ended with a brief valedictory function.

Critical Appraisal of the Meeting

The participants were urban, educated and middle class and their experience with the health system has largely (although not exclusively) been with the private and NGO sector and to a few teaching institutions of higher learning and excellence. Therefore, the deliberations of this group have limited generalisability. However the commitment of the delegates to the larger issues confronting caregivers as a whole is commendable and inspiring.

Participants had a limited understanding of both the macro realities of India, and the current mental health infrastructure. They were, however, appreciative of the information that was given to them about the realities that confronted the Indian mental health system. Most caregivers opined that they have a role to play in the betterment of services that they wished to use. It is, however, premature to comment whether this understanding will translate into action.

Most professionals recognize that not all families have the need or the inclination for emotional support through the group process, and given the diversity of caregivers and the heterogeneity of the major psychoses, a wide variety of support mechanisms will be necessary in this pluralistic society. Caregiver groups are one such mechanism that may fulfill a **small niche** in urban areas.

This meeting raised the following questions that need to be answered:

1. What kind of information and guidance do Indian families need to manage their patients? The cognitive behavioral approaches mentioned in the western literature may have limited applicability in the Indian setting, because not only are they time and resource intensive, and it is not clear whether they will suit the ethnopsychiatric illness conceptions of Indian families. It is imperative that a range of educational and interventive approaches be developed to meet this growing need for illness information and skills to manage the illness.

2. Do carers have a role in helping other families to acquire knowledge and skills to manage the illness better? In a hierarchical society like India, how will this impact professional family relationships, and will families themselves be receptive to information coming from their peers, or will they still turn to professionals for expert validation?

3. This meeting demonstrated the willingness of caregivers to take on a more proactive role in lobbying and awareness creation. It is however to be noted that the significant majority of caregivers are directly involved in the care of a relative with moderate to severe psychiatric disability which could impact the time and effort available for voluntary work. Therefore is it realistic for the professional establishment to expect active lobbying by families, or would family initiatives remain only an adjunct to initiatives driven by professionals? It is also possible that carers and groups involved in the care of more disabled patients would begin to focus their energies on long term solutions like residential facilities. How would professionals view this?

4. Should carers be involved in direct service provision (running day centers and residential homes)? Should professionals encourage carers to take up such activities? Such a role for carers is in keeping with the spirit of the NMHP, which stresses the optimal utilization of all community resources . However, there are ethical issues involved in direct service provision that would need debate and discussion.

As we can all see, the level of motivation, sophistication and partnership established in May was very high. But the headlines from India in August described "patients in a private psychiatric home" burning to death in their chains. As Dr. Murali makes clear, they were not patients, and there were no psychiatrists or other professional caretakers involved:

Erwadi and After

Dr. T. Murali, Additional Professor and Head, DPNR, NIMHANS, Secretary WAPR Indian Chapter

Introduction: There is a long history of religious healing practices all over India, followed by all religions [note the call for collaborations with religions in the report above]. Cultural acceptance is high [clearly higher for some families than is conventional psychiatric treatment], especially tolerance to behavioral deviations in the religious context.

The Erwadi Dargah is the tomb of a saintly Muslim situated in Erwadi, near Ramanathapuram in Tamil Nadu. It is almost 400 years old and provides shelter for mentally ill people from all faiths . There has been no formal arrangement made by the authorities. Devotees increased over a period of years, with the courtyard of the temple filled most nights. Few of those were Muslims, but the temple practiced traditional Muslim hospitality, accepting anyone who wished to stay and asking no questions. Families left their loved ones there for prayers, not diagnosis or treatment. As the temple filled, Erwadi Mental Asylums came into being: about 15 private asylums around the Dargah, housing about 600 persons with mental illness. These private asylums kept the inmates chained in huts. They were allowed to go for two daily prayers to the Durgah. The asylums collected for lodging: Rs1000/month. They were commercial activities, providing poor care in the lodgings. Staff did not have mental health knowledge. There were no formal mental health programs by professionals.

Erwadi Tragedy: 6th August 2001 at 4-5 AM fire broke out at Badusha Mental Home, killing 26 people, who would have been diagnosed as patients. Most of them would have escaped if not chained.

Government reacts: Sanctioned Rs.50,000 to the deceased and Rs.15,000 to the injured, closure of all asylums, arrest of owners of the asylums, started a mental health clinic - located at the premises of the Dargah. Of the 576 patients, 408 were taken by the relatives, 154 patients were shifted to Institute of Mental Health Chennai (Madras). The rest of them were deserted, many wander. The central government orders mapping of all "faith healing" centers, the Union health minister orders implementation of the guidelines for maintaining minimum standards in homes for people with mentally illness, and the Supreme Court ordered a government survey of religious healing centers with a report due in 3 months.

Public and media react: Media pays attention: many articles on care of persons with mental illness; report on similar religious centers; action by authorities of religious centers fearing police raid: chasing the mentally ill away [thus many people in need may now be homeless].

Public reacts: Blamed the government for not implementing the laws on the books already and the Mental Health Program, expressed concern over inadequate delivery of mental health services, blamed the family "for dumping the mentally ill and escaping social responsibility", criticized the government for ordering closure of such centers and instead suggested improving the basic amenities.

Professional responses: Discussed in professional bodies, which are using this opportunity to highlight the need for improving mental health facilities and to influencing the government to implement mental health programs.

Dr. Murali's report continues to offer suggestions, which probably will be conveyed in the next issue as resolutions from the Indian chapter.

CALENDAR

28-30 November 2001: Philippine Association for Psychosocial Rehabilitation. Manila. Contact Len Ronquillo, VHAMPIRONQE@vba.va.gov or Lourdes Ignacio, ignacio@ibahn.net *

4th-7th April 2002 International Conference on Mental Health & Psychiatry, Hotel Taj Samudra, Colombo, Sri Lanka Please visit www.sahanaya.lk for more details *.

26-30 May 2002 ARAPDIS (WAPR cosponsored): II Congres Internacional: La rehabilitacio psicosocial integral a la comunitat i amb la comunitat. Barcelona, Spain. Associacio ARAPDIS - Centre Documentacio, Docenia i Recerca C/ Providencia, 17, 08024 Barcelona. Tel ++ 93 415 46 17 (24h) Fax ++ 93 218 9307 e-mailcongres2002@arapdis.org www.arapdis.org/congres2002*

6-8 June 2002 WAPR Regional Conference: Psychiatric Rehabilitation Challenges and Controversies Rome, Italy.

We want to discuss some *hot* topics:

Atypical antipsychotic drugs: are they cost/effective ?

- *Evidence-based rehabilitation: does it exist ?*

Schizophrenia: is this definition still useful ?

Early intervention in psychoses: road to recovery or dangerous illusion ?

Empowerment of consumers/empowerment of relatives: conflicting goals ?

The Conference program will include: lectures, plenary sessions, discussion groups, workshops, poster sessions, and satellite symposia. The Conference languages will be Italian and English with simultaneous translation in the plenary sessions.

Registration fees

Before 30/4/2002

After 30/4/2002

Doctors/Psychologists, non-WAPR members

150 °

180 °

Doctors/Psychologists, WAPR members

120 °

150 °

Others, non-WAPR members

90 °

120 °

Others, WAPR members

60 °

90 °

Conference venue: Centro Studi e Ricerche ASL Roma, Piazza Santa Maria della Pietà 5, Roma. Information: Tel +39-06-85232453; ++39-02-64442512; e-mail: maone@tin.it or dirba@tin.it**

27 - 28 June 2002: WAPR Slovenia: Second Slovenian Congress on Psychosocial Rehabilitation: Community Psychiatry in Slovenia, CANKARJEV DOM, Ljubljana contact Vesna Svab vesna.svab@guest.arnes.si *

*WAPR representative will participate **WAPR International Board meeting

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