

I travel an enormous amount and cherish the experiences I have when I leave the comfort zone of my own culture. I can begin to see what things I think and do because that's the way everyone does them and what things I think and do because that just happens the way we do them in my community.

I had planned ever since my sons were little to take them on a long trip around Europe when they became teenagers to broaden their view of the world and themselves. As they got older, they asked me why I was limiting the trip to the small area of the world called Europe. After all, almost all of their friends who were immigrants to America came from other countries outside of Europe. I had to admit I was being Eurocentric. I expanded the scope of the trip and we visited over 20 countries in Europe, Asia, and Africa over a four and a half month trip in 2000.

When I was a psychiatry resident I got a grant to spend two months studying psychiatric practice in China. One of the things I learned from that experience was that psychiatric visits are excellent windows into other cultures. So as part of our four month world trip I arranged a series of psychiatric visits. I generally gave my four stages presentation (after a while the kids could do annoying parodies of my stories) and we often had interested personal visits with our hosts. I don't think we'll ever forget eating shwarmas at the house of the first Jordanian psychiatrist, celebrating May Day with a picnic at an Italian villa converted into a psychiatric rehabilitation program, or visiting windmills and talking about drug policies with a Dutch psychiatrist.

When we returned I gave a slide show (actually my first power point) at the Village filled with pretty pictures and stories about the mental health programs I'd visited around the world. They urged me to put down into writing what I'd seen and what I thought about it before I forgot the details. Later that year I presented this paper more formally at the World Mental Health Congress in Vancouver.

A Personal Worldwide Perspective of Psychiatric Rehabilitation

(2000)

In 1999 and 2000 I visited twenty-three mental health programs in twelve different countries (New Zealand, Japan, Thailand, India, Jordan, Italy, Netherlands, Belgium, Greece, Egypt, Malaysia and China) in an effort to broaden my cross cultural exposure to psychiatric treatment and rehabilitation and provide insights for my own work. This was not a scientific collection of facts and data from these countries, but a series of thoughtful and sometimes emotional exchanges with international colleagues. There is a systematic bias in these observations since both most of my hosts and myself are proponents and practitioners of psychiatric rehabilitation (sometimes isolated islands of this type of work.)

I was not investigating treatment strategies in a diagnostic manner (e.g. "best treatments for schizophrenia") but instead focusing on important themes in contemporary rehabilitation (empowerment, community integration, employment, families, recovery, etc.) The only diagnostically based program I saw was a young schizophrenic project in Amsterdam. Generally developmental disorders, organic brain disorders, and "psychiatric illness" are all combined. Both programs and psychiatrists were generalists and applied similar approaches to all three groups. In Japan and Greece I

saw intentional efforts to combine them to try to gain parity of funding for the more neglected mentally ill in vocational rehabilitation programs.

I am relatively familiar with the historical progression of American psychiatry from the moral treatment era in the 1800's, to the Victorian, mental hygiene institutions of the early 1900's, to the medical treatment, protective asylums in the in the mid 1900's, to our present, highly conflictual, civil rights, deinstitutionalization era. Like most ethnocentric Americans I tried to put other countries into a framework of "developing" along the same lines, but somewhere behind us. Particularly seductive was the analogy between present day Japan, with its focus on social order and appearances, modernization, hiding underlying social ills, and relying on massive institutionalization, and our Victorian era.

I had two problems with this approach: First, some countries are in places America has never been. For instance Jordan has a combination of an extremely strong family culture and a government funded modern medical model psychiatric treatment system. In America our families were already deteriorating as psychiatric medications were being developed, so we never had both at once. Similarly, in Italy, there is a very strong psychoanalytic training and practice within their psychiatric system including their rehabilitation programs, whereas, in America psychoanalysis was well into decline as rehabilitation emerged and there is virtually no overlap in training or practice between the two.

Second, many of the special things I saw were never part of American mainstream development. These included the Maori influence in New Zealand, family foster care in Geel, Belgium, a mosque based community center and mental health treatment in Cairo, the Netherlands's decriminalization approach to substance abuse, and a residential vocational training program in Japan. I began to try to organize my experiences by common issues rather than by stages of American development.

Most basically, worldwide almost all people with serious mental illnesses live with their families. Their families take on both the practical burden of providing for a disabled family member and often the burden of obtaining treatment for them. In some countries like India, Thailand and Egypt there are virtually no disability income payments from the government to assist practically, whereas, other countries like Japan and New Zealand have disability payments like ours approximating minimum wage.

Treatment availability and government funding are also highly variable. Thailand has only 300 psychiatrists for 60 million people and is only training 20 new psychiatrists each year primarily at a hospital in Bangkok set up 100 years ago by two "Moral Treatment" British psychiatrists. Egypt (also 300 psychiatrists for 60 million people) and even worse India (3000 psychiatrists for one billion people) have similar lack of available services but apparently more from a persistent "brain drain" of psychiatrists moving to America than from lack of training. In all three countries families have to pay for doctor visits, pills and even hospitalizations. Families often wait for emergencies to do so. Jordan's experience may be educative in this regard. They made a concerted effort to have more psychiatrists (40 for 5 million people) entirely paid for by the government, easily accessible, and destigmatized in the media. As an outcome they report a drastic decrease in the use of involuntary emergency hospitalizations because people are brought to treatment by their families much earlier.

For my Thai colleagues desperately wondering how they too could get government funding for mental health, I suspect the fact that the late King Hussein's father had schizophrenia was very helpful. They are, however, concerned in Jordan that the rising costs of newer medications will erode their governmental support.

These family settings are almost entirely "maintenance oriented" rather than "rehabilitation oriented". There is no expectation that the mentally ill person will be able to have their own family, productive work or independent housing. They are expected to be their family's burden lifelong. There is a relatively comfortable match between these families and "medical model" professionals in their expectations, roles, the reliance on a non-blaming biological illness model, and the pervasive use of medication to solve problems. Families and psychiatrists can work together for the patients' benefit both feeling comfortable that they know better than the "ill" person what is best for them. Again in Jordan, this can include seeing a patient at the family's request under false pretenses, prescribing medication entirely based on the family's reports, assisting families in administering medication surreptitiously, and even in one instance administering outpatient shock therapy with family approval to a patient who thought he was receiving intravenous medication. Informing the family is more important ethically than informing the patient there.

Within this "maintenance family/medical model professional" context, rehabilitation consists primarily of day treatment and sheltered workshops to keep the patients active and relieve the families' burden, and family psychoeducational and support groups. The workshop programs are staffed by mental health professionals, not actual workers in the activities (e.g. chair makers or food preparers). There is also the fairly clear expectation that the patients are not really going to progress to competitive employment. The emphasis is more on the therapeutic aspects of the activity than the training aspects. An interesting exception was in Japan at the National Vocational Rehabilitation Center that ran a 3-month residential work training program staffed by vocational rehabilitation workers that was aimed at producing work behaviors and skills in a simulated, training environment that would be competitive in the demanding Japanese business world. This was run entirely outside the family and psychiatric contexts.

Another interesting outcome in a sheltered workshop in Kyoto, Japan is that the participants, even in this protected setting, began to feel more capable and formed one of the rare consumer advocacy groups I saw. They expressed an advocacy agenda familiar to us in America: Stop psychiatrists from over-medicating and using hospitalization punitively and as disciplinary control. Stop the media from inaccurate, violent, stigma increasing portrayals of mentally ill. Increase vocational and housing opportunities. Increase consumer direction of their own treatment process.

In Greece the family education and support program I saw attached to a vocational workshop was particularly strong. They had a requirement that for the patient to be accepted into the workshops families had to attend a weekly evening psychoeducational program. It consisted of familiar communication skills, psychoeducation, (medication and illness education), and expressed emotion work, with the goal of making the family environment a healthier place to take care of the patient. The families often continued meeting after the end of the psychoeducational program as an ongoing support

group and it has evolved into the first family advocacy group there. A similar outcome also occurred in the aforementioned sheltered workshop in Japan where the families have also become an active advocacy group.

It is clear to me that while both the workshops and family programs I've described can be criticized as not truly independence or recovery oriented, they are extremely powerful programs, potentially with positive effects extending well beyond the intended ones benefiting the entire community.

In contrast there is a relatively uncomfortable match between "maintenance" families and "rehabilitation oriented" professionals. These professionals tend to describe families as infantilizing, overprotective, over caretaking and uncooperative. These professionals, myself included, do not, however, have a clear idea of what a "rehabilitation" family is or what tools to use to promote and support them. I think this area should be developed.

When family living situations break down, and it seems worldwide they rarely do, the mentally ill person becomes the community's responsibility. This can be because of violence or destructive behavior, overwhelming caretaking burden, shame, or choice. There were some particularly poignant people in Malaysia whose relatively well off families cast them off from all contact entirely because of shame and stigma. On the other hand, in the Netherlands, like in the United States, people regularly prefer to have governmental institutions take care of their family members, rather than be burdened themselves.

In countries without substantial governmental institutions a mentally ill person separated from their family may be accepted in the community's overall alms giving culture and have a stable role as a beggar. In India I learned the different between "houselessness" and "homelessness". Numerous people in India would be considered homeless in America, but they actually live with their families, have some work activity and a social and spiritual network. They are actually "houseless", not "homeless". Mentally ill people are likely to be truly "homeless" without family, work, social or spiritual roles. There seem to be different cultural tolerances for homelessness (e.g. higher in America than China), but most countries try to create institutions to avoid homelessness. In India there is a new trend where wealthy families can pay a private psychiatric institution \$50,000 to keep their mentally ill relative for the rest of their life. In China homeless people are kept in county psychiatric hospitals indefinitely.

People living in long term institutions, cut off from the rest of society, without family support and with little hope of release, are in a very vulnerable position to be abused or mistreated. Charges of corruption are wide ranging from Japanese psychiatrists being accused of overmedicating people to keep them in hospitals they own indefinitely to make money, to Indian facilities being accused of keeping people naked without belongings hosing them down to clean them, to Egyptian staff being accused of stealing patients' food to sell it. Interestingly, the Egyptian situation led to a group of consumers ("users") being put in charge of accountability and anti-corruption efforts with regular newsletters and investigations.

A particularly bad situation in Greece led to widespread system changes. An ex-prison on an island was housing several thousand mentally ill and retarded people in very bad conditions. Media publicity

targeted the Greeks' pride in their civilization charging that "civilized" people don't treat their unfortunates this way. The government's response was both to downsize and professionalize the institution making it more acceptable and to create alternative, smaller, community based institutions. These are both widespread successful responses to deplorable institutions. There is rarely substantial pressure for true community integration after these steps have been taken.

Rehabilitation within long-term institutional settings consists primarily of occupational therapy and recreational activities, sometimes including outings, designed primarily to give some pleasure and positivity to the day. Farming is sometimes added as an ongoing activity in more rural settings. For the patients, they are often the highlights of their lives.

In more transitional institutional settings more skills training is often emphasized to facilitate a return to their families. The skills training modules created at UCLA have widespread popularity in both institutional and community aftercare settings. In Malaysia, in their largest hospital the occupational therapists have gone beyond recreational activities and skills training to sheltered employment, job training and even community job placement for inpatients. One ward was converted to a self-care ward where nursing staff and other patients helped people to care for themselves rather than taking care of them. This required half again as much staff as the standard caretaking ward, but apparently led to better community functioning after discharge back to their families. (A good deal of work in that hospital seemed to be spent on convincing families that the patients could function so they would take them back.) Moving rehabilitation from an adjunctive activity to a central purpose of the ward and its nursing care was a unique conception.

In Italy I visited a well regarded one-year transitional rehabilitation program housed in a villa in the countryside. This program heavily integrated psychoanalytic work into its program beginning with lots of "preverbal" art, music and movement therapy. They intentionally created a controlled psychodynamic regression in the patients to heal their inner conflicts. Group problems were also dealt with as psychodynamic processes. The regression was reversed as the patients moved on to the community based supported housing program with more adult self-care and employment demands. (Overall, they are puzzled why America is so freely abandoning all its skills and wisdoms except pharmacological ones.)

In the Netherlands, the hospital I visited retained some older "moral treatment" ideas in its program. They included a pleasant, relaxing "natural" setting and a substantial amount of physical activity for their patients.

One of the most unusual "community maintenance" approaches I saw was the family foster care program in Geel, Belgium. Six hundred years ago a young woman was beheaded by her bereaved, presumably mentally ill, father when she refused to replace her dead mother in his bed. She was subsequently canonized as St. Daphne, patron saint of the mentally ill, and a shrine established in the small village of Geel. Over the centuries numerous mentally ill pilgrims have come to Geel seeking her intercession creating an unusually large need for this village to house mentally ill people. They began a

system where many of the villagers took in one or a few mentally ill people as a foster family indefinitely. These people were often passed along over generations within the family and considered disabled family members, included in family life and farm work. One result of having hundreds of mentally ill foster adults in a small village was a unique tolerance and acceptance of mental illness in their community. Recently life has improved for the foster adults with medications helping their symptoms, money being more available for better clothes, the ending of heavy manual farm work, and increased community “invisibility”. However, the program is dying now with the average person in their 60’s, apparently because it is seen as old fashioned and there are few new referrals as they lose business to professionally staffed community institution alternatives. The benefits of family life and acceptance by normal people do not seem to outweigh professionalism.

I am aware of two programs that have tried to adopt and “modernize” the foster family approach. One is in Sweden where one year long family foster care is offered to substance abusers as a setting for drug rehabilitation as an alternative to incarceration. The other is in Germany where foster families are trained to be one to two year long rehabilitation settings for young people with schizophrenia working towards independent living.

Professionalism, it seems to me, has been universally, uncritically adopted despite some serious downsides, including the exclusion of innovative approaches like these. In Italy, for instance only psychiatrists and psychologists are permitted to practice psychotherapy and therefore fill all the rehabilitation staff positions driving up costs. What seems a needless expense and narrowing of staff collective skills in Europe, becomes a tragic staff shortage elsewhere with families needing to bring people hundreds of miles to see a psychiatrist. In both Thailand and Egypt they are trying to get general MD’s to be first line treaters of people with mental illnesses, but failing because they’re in short supply as well. In Malaysia, the hospital has numerous staff openings because there isn’t sufficient professional staff willing to work for government salaries, but they’re prohibited from hiring any non-professionals to assist them. Even in China where years ago I saw the famed “barefoot doctors” working to provide care under a psychiatrist’s supervision for many people who would’ve been neglected otherwise, they have “successfully modernized” to an all professional staff.

In northern Europe, as in America, there has been a substantial shift from psychiatric institutions to psychiatric wards in general hospitals. Although the psychiatrist may feel more integrated; there are serious doubts if that’s actually a better environment for the people with mental illnesses. Especially if they must stay in the hospital for more than a few weeks, it becomes a rather strange and even destructive social system in which to live.

Other, mixed professional-nonprofessional programs, may be more effective, and more rehabilitative, without compromising quality control and accountability. In New Zealand, I met with a group of mental health staff, people with mental illnesses and family members. Strikingly, most people belonged to more than one of the three groups. This “blurring of boundaries” led to substantially more collaboration and less divisiveness that I am used to.

Also in New Zealand, the Schizophrenia Fellowship, a family member advocacy group began running a community-based program (drop-in center, supported housing, employment and socialization services). This experience, I believe, substantially broadened their approach and increased their effectiveness. They have gone on to strongly support the growth of a consumer advocacy movement and programs and have embraced the concept of recovery.

In India, I saw a sophisticated community based empowerment, recovery program being run in an apartment building by a combination of professional staff, trainees, consumer staff and volunteers. Similarly, in rural Egypt I saw a small private psychiatric hospital attempting to integrate itself into the local village by including farming activities, teaching local children, community volunteers and even giving small business loans to the villagers. I must mention that both of those programs had impressive emotional, inspirational leadership and direction from their psychiatrist directors that was crucial to their success. Our increasingly biological training for psychiatrists is unlikely to be preparing their successors in other innovative mixed professional – non-professional programs.

It seems there are very few people with mental illnesses living successfully neither as their family's dependents nor in a professional institution (community based or otherwise). Similarly there are very few programs designed to support true community integration in adult roles. In fact most families and institutions would resent the suggestion that they prepare people for such a life. They generally feel they are providing good homes for disabled people who are happy with them and are incapable of more. People with mental illness rarely have the organization or power to advocate for supported community integration programs for themselves and so the issue is rarely considered. Usually if families and institutions are of reasonably good quality, there is little pressure to replace them. Communism in Italy, antipsychiatry in northern Europe, and civil rights in America are rare examples of ideologies that supported deinstitutionalization. Successful implementations are even harder to locate.

Internationally, there are a number of complex issues involved in true community integration. First, many countries have a number of laws and policies that obstruct it. Personal disability income, an essential for supported independent living, doesn't exist in India, Egypt, Thailand, Malaysia or China and would have to be created. Government funding sometimes doesn't pay for psychiatric care, or will only pay for it in hospitals, or will only pay for medical aspects of care and not life support services, case management services, outreach services, etc. For example, there is a law in Malaysia that says anyone found to have a mental illness must be admitted to the hospital, at least initially if not indefinitely, for treatment. Competency laws often extend beyond criminal responsibility to prohibit people with mental illnesses from marrying, entering contracts, having bank accounts, working in "sensitive" jobs (e.g. barber or cook in Japan), getting health or life insurance, etc. These kinds of laws can often seriously restrict community functions. I would propose trying to formulate a model set of disability income, treatment funding and competency policies for advocacy purposes.

Second, there are serious concerns about danger and public safety if people with mental illness are going to be our neighbors. Many of these concerns are unrealistic and should be addressed primarily with education and media anti-stigma efforts. I was impressed that most of the programs I visited were doing active anti-stigma, and especially anti-violence education and media work. From Jordanian

newspapers, to Indian school programs, to Japanese consumer advocacy groups, to Malaysian “promotion of mental health,” to Chinese “mental health propaganda publications” this necessary work is being done.

Almost every country has some laws that say people with mental illness are not responsible for at least some of their criminal acts. It seems reasonable therefore that someone else should be responsible for them. Generally this responsibility seems to go along with life support and clinical responsibility to either families or institutions and doctors. Especially for doctors, this additional public safety responsibility is a strong disincentive for deinstitutionalization. It is unlikely psychiatrists (whether in New Zealand, Japan, or Egypt) will support community integration unless this is explicitly addressed and changed.

Criminalization of mentally ill people is a serious problem in America widely believed to be a direct result of deinstitutionalization efforts. Surprisingly to me, I did not find it to be a substantial problem anywhere I visited except maybe in New Zealand (especially among the Maori people). Places that had very inadequate mental health services did not have criminalization of mentally ill people as a consequence. I am beginning to believe that this is more a problem of criminalization, than of mental health treatment. America incarcerates far more of its population than virtually every country including its mentally ill population. (The imprisonment rates per 100,000 population are reported as USA 668, England 126, New Zealand 143 and Japan 42.) We may have a problem of criminalization of poverty (or blacks or Maoris) that is “victimizing” not just people with mental illness. Substance abuse is a major confounding factor for both violence and criminalization. All countries I visited reported less problems with substance abuse, than I experience in my work in Los Angeles. This is probably due both to underreporting (from professional and societal denial) and less problems. Criminalization was the most common response to substance abuse that I saw. For example, a psychiatrist in Thailand wanted advice on how to differentiate between schizophrenia, which is hospitalized, and amphetamine induced psychosis, which is jailed. The Netherlands provided a striking and highly publicized counter example. They believe adolescent drug “experimentation” is inevitable and that it is crucial to avoid the usual damaging consequences of drug use including contact with criminal suppliers, escalation to “hard” drugs, penalization and stigmatization. Therefore, they provide “soft” drugs openly in “safe” settings without criminal penalties. They combine this with a wide variety of government funded drug rehabilitation programs that are easily accessible. This approach would be emotionally difficult for many of us, myself included, to implement, but potentially might have a dramatic positive impact.

Third, there is a need for substantial community network creation if mentally ill people are going to “belong” in the community rather than be isolated within it. I saw a number of innovative approaches to this issue. In New Zealand, the Maori people feel a strong need to be connected to their homeland and their ancestors. Programs have been developed to reconnect people to their mountain, their village, their families, etc. “Fanna” is their extended family including village elders and ancestors and there is an effort to hold “fanna meetings” to establish community treatment plans and support networks. Ideally mental illness is seen as a problem of the entire “fanna” that all will work together to try to solve. Practically, I heard complaints that white professionals don’t know how to run “fanna”

meetings.” A “hangi” is the community center where the ancestors live and everyone gathers. I saw a “new hangi” that was built from scraps of discarded lumber by a group of troubled adolescent Maoris so they would have a place to belong and be accepted since many had become detached from their home “hangi” when they moved to the city.

A woman from the Netherlands described to me another approach to recreating lost contacts. She was supported by a “contact” family that was created for her by the mental hospital. She couldn’t live with this family, but she could share in the family life with visits, outings, holiday celebrations and rituals.

In Cairo, a mosque was being used as the core of a community center that included mental health services, medical services, clerical services, school tutoring, teen support, substance abuse services and child rearing assistance run together in an integrated way, staffed almost entirely by members of the mosque donating their time.

In general, in the context of community integration, these sorts of network building efforts are essential rehabilitative services.

Fourth, there needs to be a strong, personal psychiatric treatment presence in the community where people live. In most countries people were treated most aggressively and with the most resources in hospital settings. These settings were often very far from the community the person was from or their family. In India there was a study that reported that people’s outcomes varied inversely with the distance the hospital was from their home. Psychiatrists in Malaysia and Egypt were frustrated trying to reintegrate people into faraway communities.

In addition, the psychiatrists themselves become part of the community. Virtually every psychiatrist I met with acted “familiarily” or “personally” with their patients, not “professionally”. They said this was because they know the patients so well, they were like family or friends. They agreed that they acted differently than their university colleagues or their training, but insisted that this personal style was a necessary part of their work. I heard a psychiatrist from the Netherlands urging a “demasking” of psychiatrists so the patients would “demask” themselves too and they could really know each other. I personally believe this is a change community psychiatrists need to make and should be part of our training. Training, overall, for rehabilitation and community-based workers was repeatedly identified as a need throughout my travels. Basic skill sets, curriculum, and training modules would be widely valued.

As I came to the end of the trip, I wondered if I am still being too ethnocentric. The more I explored these cultures the more I saw that was different. When a Muslim psychiatrist in Cairo says psychotic people are not held responsible for their criminal actions because they are touched by god, like saints, is that really the same as my concept of legal incompetence? When a Malaysian family is ashamed of having a mentally ill family member, what does that feel like? When a Chinese psychiatrist who has survived numerous political changes agrees that Chinese people are less introspective and therefore perhaps less amenable to psychotherapy, what are we really agreeing about?

The one universal I am sure about is the quality of my hosts. They are all doing incredible work in very difficult situations. I may not understand what they go through, but I can feel their heart and souls, and

I was truly inspired by them. I am very honored to be their colleague and only wish that they could've had the same opportunities I had to be inspired by each other.