WAPR BULLETIN N° 30.
TABLE OF CONTENTS

Editorial:

· P.3 : Rehabilitation Psychiatry in 21st Century

Highlight:

· P.6 : Launching of Indonesian Chapter of WAPR

Special Issue:

· P.7 : Global Burden of Mental Disorders and the Need for a Comprehensive, Coordinated Response from Health and Social Sectors at the Country Level

Articles:

· P.11 : Working with Horses: Learning about Trust, Companionship and Wellbeing
· P.15 : Psychosocial Rehabilitation (PSR) in a Economic Crisis Context: The Case of Spain
· P.20 : User Controlled Research: Revisiting Relationships between Knowledge and Experience
· P.25 : Mental Disorders as Social Phenomena

Collaborations:

· P.30 : Symposium on Psychosocial Rehabilitation during the WPA Regional Meeting, Bali , 2012
· P.31 : Mental Heath Day in Spain
· P.33 : The Norwegian Branch of WAPR

Articles:

· P.34: 11th WORLD CONGRESS Milano, Italy, 10-13 November 2012
Long term mental health needs of mentally ill patients are at the heart of current priorities in service development and most of the mental health services are formulating guidelines for improving mental health programmes all around the globe. Rehabilitation psychiatry has generally been a forgotten need in many countries. However, evidence has shown that needs of people with enduring mental health problems are enormous and many people with severe mental illnesses do have long term rehabilitation needs for which long term planning and policies need to be formulated.

Rehabilitation Psychiatry is therefore assuming an emerging priority that offers a positive response to the complex and long term mental health needs of our patients. Current trends in psychiatric rehabilitation do emphasise contemporary services to rekindle hope and to open roads to personal recovery with a changing scope and patterns of mental health services. A strong need is also felt to have more emphasis on these issues in the developing countries and nations with low income resources would require some help and assistance in formulating such policies.

Looking at the historical background, the concept of rehabilitation has changed significantly over the years but has stayed consistent with the other changes that have been witnessed in the mental health programmes. Initially the needs for the rehabilitation services were advocated based on the evidence about handicaps, impairments and disabilities among the patients with severe mental illnesses. In all such concepts it was acknowledged that better outcome could be obtained if people with mental illnesses were treated and respected with dignity and offered measures for their rehabilitation. With continuous & encouraging trends of increasing attention to Rehabilitation Psychiatry, a significant improvement has been noticed in the concepts and practice of Rehabilitation. However some areas in this field are still unclear and require further deliberations as they can set the scene for exploring and looking at different dimensions of present and future strategies in this speciality.

The first issue is about the concept of psychiatric rehabilitation. The question that "What is psychiatric rehabilitation" still pose diverse views as one can find many definitions of rehabilitation in the literature. Psychiatric rehabilitation is generally defined as the activity of a set of specialised services & as suggested by World Health Organisation (WHO) rehabilitation means the application of measures aimed at reducing the
impact of disabling any handicapping conditions and enabling disabled people to achieve social integration. Similarly the term Rehabilitation has also been used in many different ways to describe boundaries, concepts and varying dimensions of a continuing process where the outcome is supposed to make patients managing their day-to-day affairs in a more effective way. With the passage of time the concept of rehabilitation has widened and included areas like meaningful occupation, appropriate housing, stability in relationship and financial autonomy. This obviously creates more confidence and imparts a lot of responsibilities to the patients emphasizing the importance of the role of “individuals” in the processes of rehabilitation.

Moving from concept to planning and classifying rehabilitation services, the practices in rehabilitation are also changing as the organisation of mental health programmes are moving from hospitals to the community with a general trend of cutting down the inpatient beds. This shift from generic community mental health teams to specialist community teams are being evaluated more critically as Assertive Outreach Teams, Early Intervention Teams and Home and Crisis Teams functioning require further evidence and directions. In many countries there is a trend of closing hospitals and it is a worry that less emphasis is given for any future follow up of specialised rehabilitation services. Similarly the experience in many developed countries about having different treatment teams is not fulfilling the promises.

Recent years have also seen increasing emphasis on the concept of social inclusion and joint partnership. With the current scenario of getting patients and users more into the processes of treatment and management, a strong need is felt for the development of a culture of empowerment that is very vital for future healing and making adjustments to the environment that ease the burden of handicap. However the true application of these ideas is still far away from the ground realities.

Similarly work and employment are being considered as important pillars of rehabilitation programmes but with the current scenario of financial recession the range and availability of such services are limited. The work schemes for people with mental illnesses generally include sheltered employment, pre-vocational training, supported employment and individual placements and support models. Vocational outcomes of the rehabilitations programmes are very important but some non vocational outcomes like improving self esteem, widening the social networks and relying less on formal mental health services also emerge as important parameters in the provision of future rehabilitation services.

There has been a lot of debate about when to start the rehabilitation programme. The traditional models of public health suggesting prevent if you can, treat if you can and rehabilitate if you can is also having some revisions in terms of understanding the future rehabilitation parameters in mental health. The importance of early intervention in treatment is supported by the evidence that early detection and early intervention can lead to better outcome & lead to recovery and improving the individual’s long term prognosis. It has also been observed that rehabilitation should not only be considered for psychotic illnesses and there are many non psychotic illnesses which would require high levels of psychosocial rehabilitation. The debate that who needs rehabilitation is now changing to who does not need rehabilitation and not surprisingly the needs for all types of mental disorders for rehabilitation are generating a lot of interest in different programmes for different mental health disorders.

The teaching and training needs in the field of rehabilitation have generally been ignored and very few structured and planned programmes are offered to the professionals in this sub speciality. Manpower development is very crucial in making any programme successful and when it comes to rehabilitation services it is generally observed that there are not many post graduate / specialist training programmes available that can bring the theoretical and practical expertise in to practice and develop formal and more structured teaching programmes in the field of psychosocial rehabilitation.

Recovery has now emerged as a new vision and during the last few decades many services are adapting this as a guiding principle & new direction in the field of rehabilitation. Current concept of Recovery is unique to the individual and highlights that the recovery process needs to be understood with a purpose and meaning for the patient, and should call for active involvement of patients with sharing personal responsibility and of course exercising a number of choices. One of the salient features of recovery movement emphasises the importance of choice rather than imposing decisions and policies on the patients. The processes also speak for positive reinforcement of success and avoid giving the impressions that the treatment and the management programmes are for punishment for failure. As the
recovery also limits impairments, disability and handicaps the emphasise continues to look at the complex needs of mental illnesses and monitor such effects on the individual with an attempt to understand the patients needs and giving importance to their personal reactions to impairments, disabilities and disadvantages that they experience as a result of the illnesses.

There has also been a continuous debate about the different aspects of recovery and the conventional models of rehabilitation. As compared to the conventional methods of rehabilitation, the literature on the recovery model emphasises on the subjective experiences of the patients, looking at their strengths, and personal meaning to their illnesses and taking a broader view of the diseases, treatments and management approaches. Many advocates of the recovery model have explained that the recovery process focuses on the evidences comprising of personal and narrative account rather than relying on the experiences of the experts.

While looking at the positive dimensions of recovery one has to be optimistic and realistic about the hopes and the expectations of our patients asking for a recovery construct. There is still not enough data available on rates of recovery as defined by the patients and the service users. Differences in the concept and the practice of Recovery oriented services also make it difficult for the professionals and the researchers to test different hypothesis linked to the recovery models. There is also no consensus whether Rehabilitation should be renamed as Recovery or Recovery needs to be kept as one of the major aspects of Rehabilitation.

Despite such controversies and divided outlook, there is a way forward for rehabilitation, recovery and long term service needs for the chronic mentally ill. It is becoming evident that with strong emphasis on the new concepts of psychosocial rehabilitation, new visions of Recovery model, development of specialised services, modifying the practice of hospital based rehabilitation and starting teaching and training programmes to improve the standard of work force would go a long way in promoting the principles and practice of rehabilitation psychiatry in the coming years.

World Association of Psychosocial Rehabilitation, an International Organisation working in the field of psychosocial rehabilitation is promoting the concept of rehabilitation, recovery and more importantly involvement of patients, users and carers in a big way. WAPR is a unique organisation and unlike many other professional associations, it gets representatives of families and patients on its executive board who take full responsibility in making decisions and formulating the policies of this International organisation. With the changing trends in Rehabilitation Psychiatry, it becomes imperative that WAPR should continue taking a proactive role in promoting the plans for “big rehabilitation” and continue assisting everyone who is involved in the process of rehabilitation & recovery. This is what WAPR is planning for its work in the 21st century.

Let us join hands and strengthen & support WAPR in meeting its objectives!

Further Readings

Launching of Indonesian Chapter of WAPR.

On Sept. 12, 2012, the Psychosocial Rehabilitation Network of Indonesia launched the Indonesian Chapter of the World Association for Psychosocial Rehabilitation, at the Sanur Paradise Plaza Hotel, Sanur, Bali Indonesia. Dr Pandu Setiawan who is the President of the Network was also designated President of WAPR Indonesia.

The launching program generated lively and enthusiastic questions and answers and as well as sharing of experiences in the work for psychosocial rehabilitation in the country, among 60 members of the Network and guests who attended. Professor Lourdes L Ignacio the President of the World Association for Psychosocial Rehabilitation introduced the objectives and the programs of WAPR worldwide. In his brief speech Dr Afzal Javed the incoming President of WAPR shared his views on the future direction of WAPR. Dr B. Tun, the President of the Indonesian Psychiatric Society and Dr Maria Tomasic, President of the Royal Australian and New Zealand College of Psychiatry, Dr Diah S Utamu, Head of the Dept of Mental Health in the Ministry of Health, joined the other mental health professionals, family members and users of mental health services in expressing the view that psychosocial rehabilitation program moving in the direction of recovery programs are most relevant.
The Executive Board,

Having considered the report on the global burden of mental disorders and the need for a comprehensive, coordinated response from health and social sectors at the country level,

RECOMMENDS to the Sixty-fifth World Health Assembly the adoption of the following resolution:

The Sixty-fifth World Health Assembly,

Having considered the report on the global burden of mental disorders and the need for a comprehensive, coordinated response from health and social sectors at the country level;

Recalling resolution WHA55.10, which, inter alia, urged Member States to increase investments in mental health, both within countries and in bilateral and multilateral cooperation, as an integral component of the well-being of populations;

Recalling further United Nations General Assembly resolution 65/95, which recognized that mental health problems are of major importance to all societies and are significant contributors to the burden of disease and the loss of quality of life, and have huge economic and social costs, and which also welcomed the WHO report on mental health and development that highlighted the lack of appropriate attention to mental health and made the case for governments and development actors to reach out to people with mental disorders in the design of strategies and programmes that include those people in education, employment, health, social protection and poverty reduction policies;

Noting the High-level Meeting of the United Nations General Assembly on the Prevention and Control of Non-communicable Diseases (New York, 19–20 September, 2011), at which it was recognized that mental and neurological disorders, including Alzheimer's disease, are an important cause of morbidity and contribute to the global noncommunicable disease burden, necessitating provision of equitable access to effective programmes and healthcare interventions;

Recognizing that mental disorders can lead to disabilities, as reflected in the United Nations Convention on the Rights of Persons with Disabilities, which also notes that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal
basis with others, and that the World report on
disability\textsuperscript{4} charts the steps that are required to
improve the participation and inclusion of people
with disabilities, including persons with mental
disabilities;

Recognizing also that mental disorders fall within a
wider spectrum that also includes neurological and
substance-use disorders which also cause substantial
disability and require a coordinated response from
health and social sectors;

Concerned that millions of people worldwide are
affected by mental disorders, that in 2004, mental
disorders accounted for 13\% of the global burden of
disease, defined as premature death combined with
years lived with disability, and that, when taking
into consideration only the disability component of
the burden of disease calculation, mental disorders
account for 25.3\% and 33.5\% of all years lived with
a disability in low- and middle-income countries, respectively;

Concerned also that exposure to humanitarian
emergencies is a potent risk factor for mental health
problems and psychological trauma and that social
structures and ongoing formal and informal care of
persons with severe, pre-existing, mental disorders
are disrupted;

Recognizing further that the treatment gap for
mental disorders is high all over the world, that
between 76\% and 85\% of people in low- and
middle-income countries with severe mental
disorders receive no treatment for their mental health
conditions, and that the corresponding figures for
high-income countries are also high – between 35\%
and 50\%;\textsuperscript{5}

Recognizing in addition that a number of mental
disorders can be prevented and that mental health
can be promoted in the health sector and in sectors
outside health;

Concerned that persons with mental disorders are
often stigmatized and underlining the need for health
authorities to work with relevant groups to change
attitudes to mental disorders;
Noting also that there is increasing evidence on the effectiveness and cost-effectiveness of interventions to promote mental health and prevent mental disorders, particularly in children and adolescents;

Noting further that mental disorders are often associated with noncommunicable diseases and a range of other priority health issues, including HIV/AIDS, maternal and child health, and violence and injuries, and that mental disorders often coexist with other medical and social factors, such as poverty, substance abuse and the harmful use of alcohol, and, in the case of women and children, greater exposure to domestic violence and abuse;

Recognizing that certain populations live in a situation that makes them particularly vulnerable to developing mental disorders, and the consequences thereof;

Recognizing that the social and economic impact of mental disorders, including mental disabilities, is diverse and far-reaching;

Taking into account the work already carried out by WHO on mental health, particularly through the mental health Gap Action Programme,

1. **URGES Member States**:  
(1) according to national priorities and within their specific contexts, to develop comprehensive policies and strategies that address the promotion of mental health, prevention of mental disorders, and early identification, care, support, treatment and recovery of persons with mental disorders;

(2) to include in policy and strategy development the need to promote human rights, tackle stigma, empower service users, address poverty and homelessness, tackle major modifiable risks, and as appropriate, promote public awareness, create opportunities for generating income, provide housing and education, provide health-care service
and community based interventions, including deinstitutionalized care;

(3) to develop, as appropriate, surveillance frameworks that include risk factors as well as social determinants of health to analyse and evaluate trends regarding mental disorders;

(4) to give appropriate priority and streamlining to mental health, including the promotion of mental health, the prevention of mental disorders, and care, support and treatment in programmes addressing health and development and to allocate appropriate resources in this regard;

(5) to collaborate with WHO in the development of a comprehensive mental health action plan;

2. REQUESTS the Director-General:

(1) to strengthen advocacy, and develop a comprehensive mental health action plan with measurable outcomes, based on an assessment of vulnerabilities and risks, in consultation with and for consideration by Member States, covering services, policies, legislation, plans, strategies and programmes to provide treatment, facilitate recovery and prevent mental disorders, promote mental health and empower persons with mental disorders to live a full and productive life in the community;

(2) to include in the comprehensive mental health action plan, provisions to address:

(a) assessment of vulnerabilities and risks as a basis for developing the mental health action plan;

(b) protection, promotion and respect for the rights of persons with mental disorders including the need to avoid stigmatization of persons with mental disorders;

(c) equitable access to affordable, quality and comprehensive health services that integrate mental health into all levels of the health-care system;

(d) development of competent, sensitive, adequate human resources to provide mental health services equitably;

(e) the promotion of equitable access to quality health care including psychosocial interventions and medication and addressing physical health-care needs;

(f) enhanced initiatives, including in policy, to promote mental health and prevent mental disorders;

(g) access to educational and social services, including health care, schooling, housing, secure employment and participation in income-generation programmes;

(h) involvement of civil society organizations, persons with mental disorders, families and caregivers in voicing their opinions and contributing to decisionmaking processes;

(i) the design and provision of mental health and psychosocial support systems that will enable community resilience and will help people to cope during humanitarian emergencies;

(j) participation of people with mental disorders in family and community life and civic affairs;

(k) mechanisms to involve the education, employment and other relevant sectors in Member States in the implementation of the mental health action plan;

(l) to build upon the work already done and avoid duplication of action;

(3) to collaborate with Member States, and as appropriate, with international, regional and national nongovernmental organizations, international development partners and technical agency partners in the development of the mental health action plan;

(4) to work with Member States and technical agencies to promote academic exchange, through which to contribute to policy-making in mental health;

(5) to submit the comprehensive mental health action plan, through the Executive Board at its 132nd session, for consideration by the Sixty-sixth World Health Assembly.
Working with horses is a novel approach to psychosocial rehabilitation in the United Kingdom. The horse as a therapeutic tool represents a wide range of opportunities for people who experience mental distress. By belonging in a group where horse therapy is used, people who experience mental distress can develop interpersonal skills and experience enhanced wellbeing and personal growth. This article describes a group for six participants, facilitated by four mental health workers, with a small herd of five Norwegian Fjord horses.

Brief history & context

Horses offer many opportunities for promoting health and wellbeing and have been used in the treatment of people, particularly children, with physical impairments for many years (Engel, 1984, McGibbon et al, 1998, Taylor et al, 2009). The use of horses in therapy began originally in Europe and has been developed in the United States where horses have been used in psychosocial interventions for a number of years (Tyler, 1994, Klontz et al 2007). The use of horses, in the United Kingdom however, for treating people with psychological and emotional difficulties is more recent (Burgon, 2003). Those who are familiar with horses will recognise and understand the ability of horses to connect with people in many ways. Horses are big and powerful, capturing human interest and imagination. They create a natural opportunity for people to overcome fears and develop self-confidence (Rothe et al 2005). Accomplishing a task involving the horse, in spite of those fears, creates confidence which can help a person to manage other challenging situations in life.

Horses in psychosocial rehabilitation

The use of horses as tools for personal growth and learning has the potential to be a unique approach within psychosocial rehabilitation. Horse therapy uses activities requiring the client or group to apply skills in non-verbal communication, assertiveness, creative thinking, problem-solving, leadership and teamwork in their interactions with horses. The approach promotes personal exploration of feelings
and behaviours, learning about partnerships with horses and others, participating in activities with the horses and processing or discussing feelings and behaviours (Mandrell, 2006). Klontz et al (2007) suggested that therapists of different clinical background would integrate work with horses within their own broader theoretical framework. For example, Engel (1984) provided an early overview of the horse as a treatment modality with occupational therapy, however this focused on the needs of people with physical impairments. O’Donnell (2007 – unpublished) conducted a systematic review of published literature into the effectiveness of using horses in a therapeutic setting. She identified six studies exploring the use of the horse in therapy and found that five demonstrated substantial improvement in several domains, including social function and performance satisfaction.

The Horse Therapy Group
The aim of the group programme was to promote wellbeing, encourage social interaction, and enhance feelings of self efficacy. The group was facilitated by an occupational therapist, a horse specialist and two mental health workers. No previous experience of horses was necessary (although one group member identified having worked with horses previously) and attendance was entirely voluntary. The group took place in a non-clinical, outdoor setting and involved a wide variety of activities outdoors with the five Norwegian Fjord horses. This particular breed of horse is ideally suited to this type of work, being extremely good natured and willing, as well as being strong enough to carry an adult without the height usually associated with horses.

The group ran weekly for eight, two hour sessions. The group was attended by six people referred by the local Community Mental Health Team. Each person was assessed by the first author to ascertain individual needs, present level of functioning and goals. Prior to the group each person was asked to complete a simple self rating scale and to identify two difficulties which they hoped the group would help them with. Examples of difficulties identified included:

Anxiety, difficulties with relaxation, lack of confidence, low self-esteem, fear of leaving the house, difficulties interacting with other people, lack of trust, inability to sleep, lack of assertiveness, difficulties mixing with people, coping with self-harm, integrating with people and making friends.

Intervention
The group members were encouraged to engage cooperatively in tasks such as; grooming, bareback riding and carriage driving activities. Using specific exercises and situations, clients learned about themselves and others by processing the horse’s response and their own feelings, behaviours and patterns during the session. For example an exercise in pairs (one client, one worker) involved putting on the horses’ head collar whilst having arms linked. This meant that each person in the pair could only use one arm and hand. The exercise involved problem solving and communication between the pair, as being a way of interacting with the horse. Other exercises involved grooming the horse (individually or in pairs) and required the client to notice the horses’ physical presence; its size, its breathing, where it liked to be touched and does not like to be touched. One person who was working at a fast and furious pace in grooming responded well to encouragement to slow down and the horse
provided immediate feedback by being calm and relaxed rather than tense. Group members were asked to work in pairs in an activity which involved leading the horse. This worked well as group members supported one another effectively and the horses responded to the commands.

Session themes
One of the sessions was designed around skills for assertiveness training with the horses. Some group members reported feeling very challenged by some of the activities, for example picking up the horses feet. Another session was designed around activities that required team work. It was observed that several clients had great difficulty giving verbal directions directly to other group members and had a tendency to speak to the horse instead. Some group members began to realise that when communication is unclear the horse did not cooperate and the tasks were more challenging.

The final two sessions focussed specifically on building confidence and working as a team. By this stage of the programme group members appeared more natural in their communications with each other and more confident in handling the horses. The very last session involved trotting the horse in the carriage which appeared to give all the group members a profound experience of excitement. Being in control of the horse in motion and feeling the power seemed to provide group members with a really positive experience.

Observations and outcomes.
Initially, group members were very quiet and interacted with each other very little. However, once they were engaged in activities with the horses they became more talkative, expressive and animated. Verbal feedback and facial expressions during activities indicated that the group members appeared to experience a sense of achievement and increased confidence by overcoming fears and completing tasks and goals well above their own expectations.

Some people had expressed feeling anxious and fearful prior to the group beginning although they appeared to overcome those initial thoughts and feelings very quickly, once engaged in activities with the horses.

One person declined to identify any personal areas of difficulty prior to the group starting. This person also attended only once (session two) where he chose not to engage in any of the activities or interact with any of the other group members. The other five group members appeared highly motivated to engage in activities during the sessions and participated in at least three activities during each session.

During the course of the group, friendships evolved and the interaction between group members increased steadily. Since the final session, three of the group members have been exchanging e-mails and photos and the remaining two have been meeting up for coffee and trips to the cinema.

Two members from the group reported feeling very relaxed as opposed to feeling agitated, which they normally experience when doing group work. This view is consistent with observations made during the sessions.

Although the group members showed great difficulty interacting with other people at the start of the group, during the duration of the group improvements became evident: personal appearances changed with more care being taken; people seemed more relaxed and confident; group members were able to interact more consistently; group members were seen to be attending to and supporting each other; were acknowledging each other and showing awareness of their own and other group members needs. Some people also appeared to become more aware of themselves and their personalities became more evident. As confidence grew, people were taking more risks and taking the initiative to lead the group at times.

Evaluation
Group members were asked at the end of the series of sessions to revisit their original identified
difficulties and comment on any changes that had occurred for them. They were also invited to comment on the experience as a whole.

Below are some of the responses.

“Once my initial anxiety about the horses wore off, my anxiety levels dropped dramatically. Being in a small group meant I was not nervous mixing with people. During the course my self confidence grew”

“It helps me interact with people through the horses”

“I actually had fun and did relax once I was at the stables. Not a conscious choice but automatic and you don’t realize it at the time. The horses do not have expectations and that relieves the pressure I put on myself. Interaction with the group just happens and strengthens with each passing week. I have photos which I look at when home which helps me when I am down”

“I have an interest in horses I have worked with them in the past it was good to have an opportunity to work with horses again. The equine therapy has provided me with the chance to meet new people. The experience was very relaxing I felt the stress was lessened for me. I would do it again if I had the chance”

“The buggy riding was exhilarating especially whilst trotting”

These positive statements from the group members represent valuable feedback on the individual experience of having taken part in the Horse Therapy Group and provide an insight to the meaning of the group to individuals. These statements reinforce the observations made by the facilitators of the group.

Summary

The group, although of short duration, appears to have had a positive effect on the wellbeing of the participants. Evaluating through observation and self report indicated that many of the aims of the group members were achieved. Follow up of longer term benefits would be valuable. It is suggested that one of the advantages of this type of programme, conducted in the outdoors, is that it removes the stigma attached to receiving more traditional mental health services. This type of therapy is potentially very empowering for clients and could be used to facilitate social inclusion in the way that social networks are encouraged to develop and interpersonal skills can be practised in a safe and supportive setting. Being with animals has proven to have many health benefits. Horses, in particular, appear to offer enormous potential in terms of promoting physical and mental well-being through occupationally focussed interventions.

References

2. Engel B (1984) The Horse as a Modality for Occupational Therapy. Occupational Therapy in Health Care, 1(1) 41-47
7. Rothe Q, Vega J, Torres M, Soler C & Pazos M (2005) From kids and horses: Equine facilitated...
Psychosocial Rehabilitation (PSR) in an Economic Crisis Context: The Case of Spain

Ricardo Guinea. MD.
President Elect WAPR, Programmes Manager MSCM. Madrid, Spain.

The World Mental health Day is yearly celebrated in Spain, with different events, including lectures, concerts, encounters with politics, and also with a demonstration in many cities, where families, users and professionals gather to claim for normalisation, and better services. But this year, the economic crisis we are facing in Spain, as in other countries in Europe, and its consequences, were in the spotlight.

Coming back a few years, the situation previous to the Psychiatric Reform in 1986 was not very good. There were not enough professionals, the professional training needed to be updated, many treatments were delivered only on institutional settings, stigma and prejudices were widespread without critic, and generally speaking, the opportunities for citizens with mental health problems to live a decent life were poor. But a very important transformation has taken place since then. Taking advantage of the political transformations in the country, under the stimulus of WAPR, and under the leadership of some highly committed policy makers and civil society organisations, the situation has brought forth very important changes.

In 1986, the new health law included mental health as a part of the public health policies. Since then, many specific PSR services have been created all throughout the country. Only to mention the situation in Madrid, in the last 15 years more than 2500 specialized services for places for people with mental distress have been created, including housing programs, supported employment and other means of social support. The same situation with some differences can be seen in many other parts of Spain, where a specific PSR network has been created. The funding for this network came from taxes, increasing slow but steadily in the period 1986-2008. Policymakers agreed to invest in PSR as they were aware of the comparatively low funding for persons in mental distress, always under the average of expense of the other countries in the European Union.

But the global economic crisis that has beaten Spain hard since 2008 has shown some weaknesses of our economic structures. We have suddenly learned that our development model based in the
construction business was not sound, and that we have lived in a bubble economy for the last years. The consequence is that the financial situation has rapidly become critical- Companies don’t easily sell their services and goods, followed by job cuts. This leads us to increasing unemployment and a sharp reduction in the state revenues from taxes, and consequently great difficulties to finance the social and health systems.

In the present situation in Spain, people try to understand what has gone wrong, but unfortunately, the answers are not easy to find. People don’t understand why our financial policymakers were unable to foresee this situation, or why the painful measures we have been facing for the last years to cope with our problems seem useless.

The impact of the crisis on the current social situation is very worrying. Unemployment is reaching very high rates (from 8% in 2008 to the current 24%). Poverty is increasing (21% of families are now under the poverty level). 374,000 families have been unable to pay their mortgages and most of them have lost their homes since 2008 (1).

Government employees (including workers in the health and the social system) face salary reduction, increase in working hours, and increased workload. Many companies contracted by the government to provide public services are suffering from the delay in charging for services. All things considered, the average loss of purchasing power can be estimated today between 10 and 20%. While the public health and social systems are suffering and struggling to resist, NGOs are obtaining a central role in providing help to the most vulnerable citizens in their basic needs. Although the situation is confusing, and there are not many official data, it has been published that over 20% of population have contacted the social services seeking for help. The social services on their side are overwhelmed, facing this emergency situation with less resources that in the past. While people demanding basic help from the social services increases (+33% elderly, +26% families with children, +10% disabled people), the available funding for social aid drops. In this context, it is disappointing to see that the main goal for policymakers seem to be how to finance the bank bailout. At the same time, economic injustices are increasing very quickly: the GINI index had dropped continuously since 1973, but in only two years it has sharply climbed to
values of 1995. (2)

In the health services, the reduction of the national budget due to the drop of state tax revenues has been dealt with efficient measures (such as prescription of generic medicines, increased work hours and caseloads). The estimated cost reduction of these measures has been around 10% of the health bill (unconfirmed, there are no official data), but it seems that this will not be enough. Unfortunately, every cut that reduces expenditure, also contributes to slow down the economy and to reduce state tax revenue, in a vicious circle.

In some parts of Spain, companies working in PSR services are already struggling to meet the payroll. Many civil society organisations (such as family organizations) had reached an important role in the provision of some services, but they no longer receive their grants. So, many of them have defaulted and their workers have been laid off. Ironically, since users organisations have never received much economic support, they are coping quite well with the situation and serving as safety networks for those who are able to join them.

For citizens with mental health problems, the first consequence of the crisis is the risk of losing part of the safety network that has been built together with them in the last 25 years. When this network weakens, the last resource is the family. In Spain, as in other countries where people have usually strong family boundaries, the family is a very important social support. Most people (about 80%) with severe mental illness remain living with their families, most of the time due to economic dependency or unemployment. Interestingly, many of them have been able to develop useful roles, as carers of their elderly parents. The PSR systems were previously able to support the stability of these arrangements, visiting and monitoring the families, enhancing their contact with services and with family psycho-education. But some groups of the most vulnerable users with fragile community boundaries (homeless, immigrants) are at risk of losing all contacts with the support programs, including the access to medication. The foreseeable consequences will be the increase of relapse, increase caseload in acute wards and crisis services, increase in homelessness, and increased demand for long term institutional care.

A second consequence is that the concern about the economic cost of the services is leading to the risk that administrators only consider the economic costs in contracting services, regardless quality losses. Some government agencies are planning to renegotiate the contracts with the companies that are currently delivering PSR services paying attention only to the economic cost. As it has already happened in other social areas, companies without any expertise in PSR see the “opportunity of business” gaining the new contracts making very low bids, paying very low salaries and hiring workers with low qualification, with the risk of poor quality in services. This can be dramatic, because in PSR, quality in crucial for ensuring supportive and recovery oriented environments.

A third consequence is that detractors of the welfare state model are cumulating arguments to question it. Forgetting that it by no means has not been the welfare system that caused this crisis (actually, it has been caused by a a poor finance model and management) some stakeholders blame the welfare system as unsustainable and claim the reduction of the social investment. Some measures in this direction have already been implemented: many basic medicines will not be provided anymore by the health system, the right in the access to health attention for some critically vulnerable groups (as illegal immigrants) has been clearly questioned. In a first stroke, the weakest members in the community (the elderly with low income, the poor, children in poor or dysfunctional families, homeless) will suffer the consequences. But it will be the whole community that will suffer from the deterioration of community welfare standards. Changes affecting children’s’ education today will lead to long lasting social deterioration in coming years. This political discussion has been raised, and will need to be further addressed in the future.

There are reactions from the civil society. Discontent is very large, and we are witnessing the
emergence of organised movements against these policies. In our field, some NGOs have managed to deliver basic medicines to the citizens with mental health problems with difficulties to get them, and some doctors claim they will continue receiving patients despite their irregular administrative situation.

Defenders of welfare state claim that in Spain, comparing the sovereign debt in the beginning of the crisis with other European countries, the debts were quite low (In 2007 it was only 36% of the GDP, compared to 62% average in the Europe Area; source: European System of Central Banks, 2011). The state expenditure in social services or in the health services, albeit increasing from 1986 until 2006, has always been under the average in Europe, even in the best years of the economy. In the health services, the expenditure in 2006 was 8.4% of the GDP, less that the average 9.6% in the UE-15 (OECD Data 2008). And the average social expenditure in Spain was 25% of the GDP in 2009, compared to 29.5% in Europe 27 (Eurostats 2012). The recent evolution (estimated data) suggests now an important reduction of the health expenditure (10%) (1), the official data from national budget 2013 announce that the overall social protection expenditure will decrease by 4.5%.

Since most factors in this situation depend on the economy of the country, there is not much that we can say about how the PSR system should evolve in order to cope with the crisis. Funding will decrease and certainly, efficiency is always an issue, but as it has been revealed, the social services(which PSR network is a part of) cannot be blamed as a factor in triggering the crisis.

However, it is clear that we cannot use resources we do not have. The crisis has vanished part of the resources we had in the past and it is necessary to face the new situation until the crisis is over. In an attempt to maintain the PSR networks of services with fewer resources, managers and policymakers are raising the issue of a voluntary reduction of wages in exchange for keeping the services (and jobs). These discouraging measures will require leadership and well-funded values in the teams, but hopefully, with them it might be possible to maintain most of the structure of services created since 1986.

In the new scenario, those services that will effectively enhance service users’ autonomy, responsibility and self-help will be more valuable, especially if they are able to create groups for mutual aid.

Enhancing the natural networks including the person with mental health problems(as well as families or social networks) will also be important. There are already some small experiences in that direction. There’s a challenge to find effective ways to achieve these goals.

Organisations working in PSR should also be aware of ensuring that in the new scenario the cuts will be reasonable, and that the people with mental health problems are not powerless in relation to other groups.

In the beginning of the global crisis in USA, the sociologist Norman Birbaum commented that ironically “a crisis that questioned the future of capitalism will end questioning the future of the states”. As it has been suggested, we are now discussing the sustainability of the PSR system in Spain, as a part of the welfare system, when it has been the failure in regulations of the finance capitalism model what has lead us to this economic disaster. We can discuss the way we will save our PSR system, but as some global political forums are suggesting, indeed the real discussion is what model of society and economy we want, and whether our current political structures can lead us towards the desired outcome.

As Madianos (4) discusses, it is likely that the negative impact of changes in our globalised economy will influence negatively on prevalence, course and outcome of schizophrenia, and changes of a globalised economy will have effect on the
countries situation by: “…increasing unemployment rates (investments moving to cheap labour countries), privatizing social institutions (less social welfare state), high social mobility, transforming family structure, and marginalizing socially disadvantaged groups (unskilled workers, minority groups and disabled persons). And “…the marginalization-alienation of the less economically advantaged social groups, including mentally disabled in the metropolitan areas of western countries increases the risk for developing a chronic mental disorder or worsening an existing one”.

In the countries where the social investment is being restricted, we cannot ignore that a conflict and dissatisfaction between the citizens and policymakers may lead to a deep (and expensive) social fracture, because social policies as PSR are not a technology but funded in a philosophy of humanistic approaches and social awareness and agreement.

These ideas lead us to look beyond the situation in Spain and the other European countries in economic crisis, and beyond our field of specific expertise to consider how global basic values of societies impact on health and wellness. The 2011 WHO report “WHO Mental Health Gap Action Program (mhGAP)” (5) highlights that “In all countries throughout the world, there is a wide gap between the high prevalence of mental, neurological and substance use disorders and the low proportion of affected individuals that receive adequate care”. The report also stresses, “Average global spending on mental health is still less than US$ 3 per capita per year. In low income countries, expenditure can be as little as US$0.25 per person per year, according to the WHO’s Mental Health Atlas 2011”.

The final statement of the WHO conference in Rio de Janeiro 2011, “Declaration of Social Determinants of Health” (6), points out “early years' experiences, education, economic status, employment and decent work, housing and environment, and effective systems of preventing and treating ill health”, as critical factors of health, and recommends to “…support social protection floors as defined by
countries to address their specific needs and the ongoing work on social protection within the United Nations system...”, considering that, in the mid term, as some academics have shown (7), a welfare system in a country, rather than an expense, is an investment in better health, longer lives, and better opportunities for education for its population. All things with a good impact on economy, because, as an example, better education today means increased future productivity, or longer lives may work as stimulus for investing in education and making savings in pension funds.

As Stiglitz (8) writes "some global public goods (as may be equitable access to food, water, education or health services) should be produced and distributed to the population, but they are not, and some global externalities (as might be sustainable development and environmental care) should be taken into account, but are not. (...) However, the international scene is often used to find solutions to problems that are unrelated to the people’s circumstances and the actors of these institutions try to manage opaque and secretive resolutions, all of which wouldn’t simply be possible to carry out in the framework of a national democracy”.

Similarly, the UN “Bruntland” Report (9) suggests that “A first step may be for governments to abandon the false division between 'productive' or 'economical' expenditures and 'social' expenditures. Policymakers must realize that spending on population activities and on other efforts to raise human potential is crucial to a nation's economic and productive activities and to achieving sustainable human progress, the end for which a government exists”. Are we here claiming for a utopian world? May be. But the global financial catastrophe from 2008 onwards seems to support those who think that the market economy by itself cannot meet the needs of the population.

References
1. There are no official recent data about the evolution of the economic crisis in Spain. If no specific reference is made, the quoted data come from national NGO observatories of have been published in national newspapers referred to “unconfirmed sources” from different governmental agencies.
2. Reference to GINI index in Spain: http://esmola.wordpress.com/2012/02/07/pib-y-gini/
Introduction
There is now a growing interest internationally in user involvement in research. In the UK, for example, this is reflected in the government’s establishment of a body to help advance it in health, social care and public health research, the National Institute for Health Research Involve (http://www.invo.org.uk/). It is also signified by increasing requirements among both state and independent research funders that evidence is provided of the involvement of service users in designing and undertaking research. There is also now a growing body of such research projects and discussions about such research.

There are three broad overlapping approaches to such involvement in research projects which have been identified. First is user involvement research, where input from service users is added to existing research arrangements. Second, is collaborative or partnership research where service users and/or their organizations and researchers and/or their organizations jointly develop and undertake projects and third user controlled research where service users and their organizations initiate and control the research. The sweep of such involvement can be large, extending from the identification of research questions and focus, through undertaking the research, to shaping dissemination policy and follow-up action (Faulkner and Nicholls, 1999; Faulkner and Layzell, 2000).

Service users are also now involved in the broader processes and structures of research, for example, having a role in research organizations and bodies, the selection of research projects for funding, research training and education and peer reviewing for and on editorial boards of journal and other research publications (Beresford 2003; Beresford and Carr, 2012).

User controlled research
User controlled research can be seen as the most developed domain for such user involvement. In the UK, it can be seen to have grown initially from the disabled people’s movement as emancipatory disability research and more recently has spread to and been adopted by other user groups, including, mental health service users, where it is known as ‘survivor research’, people with learning difficulties...
and older people (Campbell and Oliver, 1996; Campbell, 1996; Lindow, 2001).

Disabled people’s and social care service user organizations and movements have emphasized two overlapping concerns in research and evaluation: what research is for and where control of research lies. These are

• Changing and equalizing relations between researcher and research participant (Oliver, 1992)
• Change making as the purpose of research linking research to action – both to empower the individual and bring about broader social change (Barnes and Mercer, 1997; Barnes, Morgan and Mercer, 2001; Mercer, 2002).

This reflects liberatory and democratizing models of user involvement developed more generally by service users, their organisations and allies in relation to the development and control of policy and practice.

**Issues raised**

All forms of user involvement in research raise philosophical and methodological questions. But these have tended to be focused on user controlled research, because it is, of course, explicitly political. It offers itself as an essentially political activity, rather than a neutral ‘fact-finding mission’. It is concerned primarily with improving people’s lives rather than solely with generating knowledge. Thus disabled and service user researchers, organizations and movements have tended to see user involvement in research and user controlled research as part of a process of developing their own knowledges and discourses – towards that goal of liberatory change.

As a result, we can expect fundamental questions to be raised about the relation of emancipatory and user controlled research with traditional positivist research values of ‘objectivity’, ‘distance’ and ‘neutrality’, even though qualitative and new paradigm research has made its own challenge to these. Findings from such involvement will need to address questioning of them as partisan or biased. Questions will also be raised about the problems
which user controlled research raises because one sectional interest may be seen to be dominant - that of service users. There will be concern to consider it in relation to criteria of ‘validity’ and ‘reliability’. There will be issues to answer about who is a service user. We will need to consider concerns around the validity of different knowledge standpoints and knowledge claims; the ownership of knowledge and its interpretation (to which we will return later); dominant hierarchies of credibility; the nature of the relationship between knowledge and direct experience; the meaning of ‘evidence-based’ and what counts as ‘evidence’ (Beresford, 2003a).

In a research world which still sees the randomised control trial, or ‘RCT’, and systematic reviews as the research ‘gold standard’, the principles of user controlled research are unlikely to be seen by many mainstream researchers, research organisations, funders and commissioner as providing a sufficient, sustained and convincing argument for its rigour and reliability. The emphasis in mental health research, for example, is still on positivist values of ‘balanced’, ‘detached’ and ‘scientific’ research (Glasby and Beresford, 2006). The essentially partisan and political nature of user controlled and emancipatory research, committed to improving people’s lives, continue to be seen by many mainstream researchers as weaknesses which qualify their usefulness in providing rigorous routes to the provision of reliable knowledge. At the same time service users are developing both qualitative and quantitative research approaches and changing them by bringing their ideas and experience to bear and making them more participatory.

As has been indicated, service user controlled or emancipatory research, is not the first research approach to challenge traditional methodological frameworks. What distinguishes user controlled research from traditional approaches, though, is the emphasis it places on experiential knowledge; the importance of service users developing and being involved in research because of their direct personal experience of the issues under study (Sweeney et al, 2009). Thus, service users are seen to ‘know what they are talking about’ because they have directly experienced it. However, this flies in the face of traditional research values of ‘neutrality’, ‘objectivity’ and ‘distance’. By these criteria, the ‘knowledge’ of service users will automatically be seen to have less value, less credibility and legitimacy. Historically, we know this is what has happened. The knowledge ‘claims’ of researchers, academics and analysts without such direct experience has been attributed higher status.

**Relations between experiential knowledge and research values**

This has some disturbing implications, which so far have tended to be overlooked. Where values associated with research and the development of knowledge about people and how they live, prioritise being distant and separate from the subject under consideration, it raises major concerns for the people who are the subject of such research or about whom knowledge is being sought (Beresford, 2003b).

If an individual has direct experience of problems like disability, poverty or using the mental health system; if they have experience of oppression and discrimination, when such research values are accepted, what they say will also be seen as having less legitimacy. Because they will be seen as ‘close to the problem’ – it directly affects them – they cannot claim that they are ‘neutral’, ‘objective’ and ‘distant’ to it. So in addition to any discrimination and oppression they may already experience, they face an additional problem. They are likely to be seen as a less reliable, less valid source of knowledge. It is possible to see how this worked for a long time against women and children who were subjected to sexual and violent attacks. In male dominated societies, these were not placed high on public or political agendas. The knowledge and experience of women and children who experienced such attacks were not listened to or valued. It is only in recent years in western societies that issues like child sexual abuse, domestic violence and rape have begun to be acknowledged publicly and formally as serious social problems.
What this means effectively is that if someone has experience of discrimination and oppression they can expect routinely to face further discrimination and be further marginalised by being seen as having less credibility and being a less reliable source of knowledge. This is likely to have the effect of further invalidating people who are already heavily disadvantaged. This problem is magnified for a group like mental health service users, because their identity is generally devalued and they are frequently treated as though their knowledge is suspect because they are seen as irrational and lacking reliable perceptions and judgement.

However, traditional devaluing of experiential knowledge by mainstream research flies in the face of much of the rest of human experience, where generally, people learn to place a premium on finding out about things from those who have direct experience and drawing on their first-hand knowledge. In colloquial terms, we seek the expertise of people who have ‘been there, done it, got the tee shirt’ – people who ‘know’. Thus in accepting traditional research judgements of knowledge based on direct experience, both individual and collective experience, we seem to be disregarding the authority which we have usually learned to invest in other areas of human activity and life. Traditionally, conventional research and researchers appropriated the experience of research participants arguing that they themselves were better equipped to interpret it because of their own ‘distance’ from the experience.

While such assumptions may be helpful in the natural sciences (and even this view demands further scrutiny), it is questionable whether they can be taken as given in the human and social sciences, which are so closely based on human interactions and subjective interpretations.

**Questioning prevailing assumptions**

It is perhaps now time to begin question some of these assumptions. It is likely to be helpful for researchers more generally to do this. One assumption which particularly needs to be re-examined is that: “The greater the distance there is between direct experience and its interpretation, the more reliable it is”.

---

*WAPR BULLETIN Nº 30

NOVEMBER 2012*
It is perhaps time instead to explore the evidence and the theoretical framework for testing out whether:

*The shorter the distance there is between direct experience and its interpretation (as for example can be offered by user involvement in research and particularly user controlled research), then the less distorted, inaccurate and damaging resulting knowledge is likely to be* (Beresford, 2003b).

It is not being suggested here that this alternative is necessarily ‘more valid’ than the traditional understanding. There may also be a potential problem in trying to use a conventional hypothesis or research tool for exploring what is essentially a qualitatively different research approach. But the aim here is very much an initial one, of trying to explore modern service user controlled research approaches in ways which may be helpful both to service user researchers and mainstream researchers. In addition, if we seek to test out this alternative hypothesis, we will undeniably have moved from assuming that there is objectivity in social research. But given the theoretical and methodological developments over the last 20 and more years, it seems helpful to address this widely accepted reality and acknowledge the value of including the subjective in our approaches to and understanding of research and knowledge formation. Developing such a hypothesis may offer us intellectual and academic arguments, to complement current moral arguments for extending service user involvement in research and particularly in service user controlled research. It may equally lead us to adopt a more critical response to it and help us to differentiate helpfully between different approaches to service user involvement in research.

**Conclusion**

Discussion about user involvement in research and user controlled research thus focuses attention on a number of underpinning issues for research. While these issues tend to be associated with such new paradigm research, they are truly ones which all research must address too. But they must nonetheless be addressed by those with an interest in user involvement. Advocates and critics of user involvement in research alike both feel that the interest such user involvement has attracted and the progress it has made, mean that it is now time to examine it systematically, to explore its strengths and weaknesses, benefits and disadvantages (Cotterell et al, 2010; Adebajo et al, 2011; Barber et al, 2011.

I would want to stress the need for the systematic and coherent evaluation of user involvement in research. This needs to be a process of evaluation in which service users, their organizations and user researchers are involved in fully and equally. The strengths, weaknesses and impact of such research needs to be explored. Involve will shortly be publishing the first study of such impact.

Service users worry about the future of user involvement in research. They worry that such involvement may only be a short lived enthusiasm. They are concerned with ensuring its effective safeguarding for the future. But there is one more point that needs to be made. As I have said, there is now considerable interest in and support for user involvement. Yet so far there have been very few user controlled research projects comparatively speaking. Little funding has so far gone towards them (Sweeney et al, 2009). It is important that the full range of approaches to user involvement in research, from the most limited and tokenistic involvement, to user controlled and emancipatory research are supported and then included for evaluation. We must not see user involvement as monolithic and uniform and either support or reject it accordingly. Democratic approaches to involvement in research face the same barriers and inequalities that democratic approaches to participation have faced more generally. These must be challenged and more support given to such research approaches if systematic evaluation of user involvement in research is to be possible and meaningful.
This paper draws on a previous presentation:


References


8, No 1, pp36-46.


We now know that mental disorders are shaped by social experiences and its social context, in much the same way, as they shape these same experiences and the environment where they happen. As consequences of troubling and traumatic social events, the characteristic features of anxiety states and immobilizing fear, of helplessness and sadness, those of the more serious experiences as hallucinations in the unreality of sensory experiences as well as in unrealistic delusional beliefs, are acknowledged, described and experienced.

We also know that the pain and suffering from these disorders are not limited to the individual who suffers, but extends to his family and his social network composed of friends, relatives and co-workers, signaling the fact that such disorders are not only felt with, but shaped by the intensity of the social forces around it. Such forces are understood as occurring within a specific social space, encompassing a web of social relationships and structures that in turn transform such experiences. Although felt intensely by the individual, the suffering that is experienced is not just an intra-psychic conflict or existential angst. It is also the devastating experiences, of helplessness and powerlessness in the face of massive community destruction in disasters both natural and man-made, of failed or lost relationships, of frustrations and dissolutionment for lost opportunities and social failures, of intense fears due to hostility and violence from others, of dehumanizing experiences due to discrimination, stigma, isolation and the constant agony from the lingering deprivation in poverty. As can be gleaned from all these, the family and his social network of relatives, friends, neighbors and co-workers, are involved and just as equally burdened. All these are felt as threats to the personal integrity of the individual, as well as the environment around him because the impact of the distress push individuals and those around them to the limits of their endurance and test their abilities to sustain their balance and stability.

What therefore has become clear is that a mental disorder is not a discrete problem, being experienced outside the course of everyday life. It is part of a complex set of circumstances that clearly shows the mutual transaction of the person and his social environment. The experience of a mental disorder combine the reality of mental distress as described by the individual and the range of subjective phenomena he experiences. It therefore is simultaneously an objective and subjective experience. A. Kleinman refers
to this as an experience of social suffering. The World Mental Health Report, (2001), elaborates on this suffering as within the web of such global and individual experiences that are interlinked like poverty, isolation, trauma, victimization. All these are understood as the cause and as well as the outcome of mental disorders.

Suffering is a powerful term, one that right away focuses attention on a total human experience. These experiences are the pain of physical illness, the mental angst of mental and emotional distress, the social disharmony in failed relationships, and the spiritual experience of meaninglessness of one’s existence. Social suffering is understood to be that experience when pain as a result of these collective human problems and understood to have their origins and consequences in the devastating injuries that social forces inflict on human experience. It is clear therefore that the experiences of individuals who suffer from mental health problems or mental disorders are experiences of social suffering.

Although the biological mechanisms in the causation of mental disorders have pointed quite clearly to pituitary-hypothalamic dysregulation, dopaminergic sensitization and alteration of genetic expressions, persons suffering from mental disorders do not come complaining of for example, “the dysregulation of my pituitary-hypothalamic circuit”. They come and articulate what they recognize as the consequences of the impact of persons and events on them. Their focus point mainly on those around them, i.e., the social perspectives to their mental symptoms.

Two important social perspectives are considered. Firstly, that a mental disorder is not intrinsic in individuals but a social construction. The labeling phenomenon related to the concept of deviance comes to mind. Deviance is understood as not intrinsic to particular behaviors but is merely a creation of social groups. The so-called symptoms are regarded as violations of the norm and therefore norm violating behaviors or deviant behavior. Once the deviant acquires the label, the individual is treated accordingly, and in the process will be treated differently, which increasingly takes stereotypical features, based on the group’s definition of a mentally disordered individual. This label continues and becomes amplified in the group. “Becoming a
"patient" was described in Goffman’s “Asylums” as the process of how a mental disorder is not to be understood as within the person but is created by society. Secondly, the social determinants of mental disorders have been widely understood and identify social structures as causing social strain and the person’s social experiences as sources of social stresses. Structural strain points to the origins of mental disorders in the organization and structure of society. The classic studies of Durkheim have shown for example, that the co-existing states of social disorganization and normlessness or anomie are closely linked to suicide during periods of rapid economic and social changes. Earlier studies on social class and mental illness continue to be pursued to confirm the close links of high rates of mental disorders among social classes as well as their utilization of mental health services. These studies have shown that the consequent mental disorders are linked to other facets of the social disadvantages inherent in these social classes, creating a pool of problems that can not be addressed individually or splintered into neat diagnostic criteria.

Understanding stress as the body’s response, (alarm reaction, resistance, and exhaustion/adaptation) to anything that represent a threat or insult to it, finds its relevance as the basic framework with which social stressors impact on individuals to increase the risk for mental disorders. A whole range of problems spanning through the life span as social stressors, have been identified. Studies have shown how context moderates the impact of stress arising from negative events like loss or its threat and chronic difficulties, like economic hardship, and how these problems interconnect to sustain and maintain mental distress. Yet, their outcome as mental disorders remain unclear, especially as one considers that the prolonged experience of mental distress does not stand apart from the flow of everyday life. The question remains “Is it normal sorrow or depressive disorder? Are among some of these questions.

The conceptualization of distress and suffering remains an issue in the social perspective of mental health problems and mental disorder that remain unclear. Those like us who respond to provide a psychosocial program in the aftermath of disasters are confronted with this issue all the time. How does one conceptualize the experiences of a community of people in disaster affected areas who have suffered losses through death, complex experiences of loss of loss of homes, livelihood, neighborhood even ancestral domain, and manifest intense sadness, even a mental breakdown?

The social and cultural environment within which mental disorders occur, likewise shape its manifestation and the responses to these. Culturally held beliefs influence the responses and help seeking behaviors. Ethnographic studies have been robust in describing how mental illness is conceptualized and managed cross-culturally and in providing explanatory models of illness as a basis for understanding the ideas about episodes of illness that the patient, his relative and the clinician himself bring to the clinic.

What has become clear in the interconnectedness of the experience of suffering from mental disorders, here understood as social suffering, is that it is inadequate to see disease/illness/disorder as affecting a single person, because the pain extends beyond the patient, and outwards into his social space.

The challenge to the mental health professionals, psychiatrists and those involved in psychosocial rehabilitation is the continuing challenge to define normality vis a vis deviance from the norm, or abnormality. Would these be viewed from the point of view that what is abnormal can only be viewed as a description of a discrete set of diseases referred to as mental disorders. This is seen in the current system of nomenclature and classification of mental disorders, which presents a set of assumptions about understanding the causes and treatment approaches for these disorders that focus predominantly on the individual alone. This system in its symptoms categorization and classification clearly individualize and medicalize which in most cases become the basis of time-limited psychotherapy or even “quick fix” with psychopharmacologic agents, stripping the
patient the true essence of his suffering from the disorder. Because, the disorder must be viewed beyond the individual because it has a broader social context.

The 11th World Congress for Psychosocial Rehabilitation has for its theme: “Change: in thinking, practices, services”. The theme is right on target if concepts go beyond the current system of looking at mental disorders from the viewpoint that focuses on the individual alone. That, the individual’s suffering from these disorders is actually an enduring experience of social suffering because his suffering is really part of a whole collection of human problems that are the causes and the outcomes of the pain and conflicts that external forces inflict upon him, which, in turn leads him to confront and influence that same social environment to respond accordingly to him. Policies for health, care systems and interventions locally and globally therefore extends beyond the individual to the family and the social network, clearly collapsing the traditional distinction between health and social problems and therefore the need to simultaneous address both health and social policies. For example, policies covering the social disorganization of urban slums and its conditions of poverty, high risk for violence, broken families need to be seen as settings for prevalent chronic illnesses, suicide, depression, psychosis, drug abuse among the young.

It becomes crucial to address these issues because of the increasing pace of social changes throughout the world... notably economic crises, mass migrations, technological advancements. The latter has in fact revolutionized patterns of communications. Presently the world continues to be in the midst of economic downturns, high rates of job loss, violent protests to the call for further austerity measures and sacrifice from the same people who are already suffering, from these and from loss of fund support for health and mental health services, resulting in poverty and general uncertainty. In many economically disadvantaged countries like mine these economic pressures continue to cause family breakdowns as a result of the massive push for overseas employment and migration; in others this displacement of people result in internal displacements following disasters, again causing disorganization of the basic social unit and possibly continuing threat to the social disintegration of communities. At the same time the current revolution generated by advances in telecommunication technology have generated the phenomenon of social networking which has transformed patterns of communication and the formation of relationships. The social networking that prevails has replaced face to face interactions and relationship offering a variety of ways in gaining access to information especially at personal levels. These have various implications to mental health and risks for mental disorders.

Social suffering prevails, as mental disorders become clearly understood as a social phenomenon. This defines the changes that need to put in place, in the way we conceptualize mental disorders, how we assist those who suffer from them and provide the necessary policies that provide for a system of interventions that necessarily goes beyond the individual patient, because this necessarily needs involve his network of family, relatives co-workers, and considering also the current advances in telecommunication technology, even the patterns of forming relationships have changed because now includes access beyond the traditional the face to face milieu in forming and nurturing social relationships, and out to cyberspace. While this offers exciting almost limitless possibilities for change, its implications to the promotion of well-being and mental health as well as the broadness with which the suffering from mental disorders is understood calls for concerted efforts to truly look as mental disorders as social phenomena, in much the same way as we now see health in general as a social concern.

The changes that are expected need to address the suffering of the person with mental disorder, which is to be understood as social suffering, hence carrying a broader dimension because it is also in the context of the larger social environment.
The “CASA VERDE” is a Supporting, Prevention and Monitoring Program for children whose parents have serious mental illnesses. It is developed by Fundación Manantial on April 1st 2011 (in line with the Declaration of the EUFAMI Congress held in Lithuania “The forgotten children”), with the aim of preventing future psychological and social problems for the persons with a significant risk of future distress, suffering and psychosocial problems.

The team is multi-professional and consists of two psychologists, one social worker, one social educator and one children educator with special responsibility for pregnant women with mental disorders. Specialised services are offered to the mother and her child and to the comprehensive family environment, in order to enable a stable emotional base for further secure attachment and an appropriate evolutionary development of the child. In addition to the prenatal support to pregnant women and first care to the mother and her newborn child, we must also point out the emphasis of coordination and support to the institutions involved in youth protection (specialized assessment of the situation, support and advice hosting families….).

The Program is implemented in Madrid districts of Vallecas Villa and Vallecas Puente (333,438 inhabitants) thanks to the collaborative agreements signed in this regard both with Madrid City Council (through the Directorate-General of Family, Childhood and Volunteerism) and the Community of Madrid (through the Regional Office for Mental Health within the Health Care Regional Government).

Children and pregnant women come into the Program from the Mental Health Centers of the mentioned districts, from the Child and Family Care Centers (CAI and CAF) and from the Social Services Centers of both districts. We also collaborate with Madrid Courts, with the professional teams for family support and with the community organizations for leisure and free time.

The “CASA VERDE” is located in very central premises of Vallecas Districts and its professional team provides accessible and available help, are flexible in their approaches and offer home as well as a variety of community services. The service environments are furnished and equipped with children in mind, trying to create a cozy and safe atmosphere.

Throughout these last 18 months, “CASA
VERDE” has attended 50 children, 11 pregnant women and 51 mothers, fathers or caregivers with mental illness. We have also enjoyed 9 births! We currently have 18 families on the waiting list. The activities we carry out consist of assisting mothers during pregnancy, childbirth and first months of the baby’s life, provide psychotherapy and training in parenting skills, early stimulation as needed and support.

The program “CASA VERDE” represents comprehensive clinical expertise and experience and is also supported by a research project funded by Fundación Manantial and carried out by the School of Psychology at the Complutense University of Madrid. This concluded that up to 45% of persons with mental illness end up losing the responsibility of their children. It has been carried out with a methodology of Pilot Program which evaluation is currently being made by the School of Psychology at Comillas University in Madrid. However “CASA VERDE” is much more than just figures, numbers and statistics. It is a firm stake and commitment of Fundación Manantial and the professionals who each day develop the program to allow mothers and fathers suffering from mental health problems live fulfilling lives raising and enjoying their children and, at the same time, ensure
“Mental Health Day in Spain”
A statement from “Federación Madrileña de Asociaciones Pro Salud Mental”
(FEMASAM)

The Madrid Federation of Mental Health Associations (FEMASAM) was created 25 years ago. Thanks to the illusions of those affected, their families and friends, and the support of mental health professionals associations, there was a radical change in the way we understood and lived mental illness.

In the beginning of the psychiatric reform, we noted that there was a great lack of resources for mental health. Fortunately, this lack has been partially solved, although the gains have not met our expectations, and there is still a long way to achieve our goal.

Long before the community network of public services was established, there were the associations. They have been working for over a quarter century, claiming for transformation and investment in mental health, and focusing on the future. Mental disorders began to be addressed from the perspective of community multidisciplinary treatment and rehabilitation, as core elements of the intervention.

And so the change began, with few resources but with dreams, hope, confidence, awareness of the
obstacles and of the need of years of work.

25 years after, we now see the changes gained and the thousands of families that have benefited in many ways: better lives, access to work, better opportunities, emotional support, achievement of a significative improvement in quality of life for people affected by a mental health problems and their families.

Associations also have matured, along with people in them. From a first paternalistic approach, each association has learnt that everyone has to write his own story, and the utopia of independent living has been transformed into reality, step by step.

We cannot forget this day those who are no longer with us because the pain took them, but we are happy for the number of suicides that we have contributed to avoid. (We know that currently the highest rate of unnatural death between 20 and 55 is due to suicide). We feel encouraged for all hospitalizations that we avoided: statistics show that when a family join an association, the probability of hospitalization of their ill relatives decreases. In the associations, patients and families are informed about their rights and the existing resources, and they learn how to manage the family relationships to prevent relapse.

In this time of crisis, with this manifesto in Mental Health Day, we urge authorities, governments, policymakers and public at large, to support the maintenance of all this work, to support the International Convention on the Rights of Persons with Disabilities, adopted by Spain in 2006. And we demand real equality of treatment for people with disabilities and, in particular, with mental illnesses, real equality in the access to work, education and live opportunities.

We claim and ask policymakers to think what would happen if there were no associations, if all persons or families to whom we serve without labels were found again without support and partnership, in the loneliness of the road.

We, the associations, are facing a genuine bewilderment in the current circumstances, where workers are not paid for months, when due to the fund cuts we cannot pay the telephone and debts make almost impossible for us to continue working and continue giving support our families. It is not difficult to conclude that all the work we have done and all the pain and expenses we have avoided are not sufficiently recognized by governments and society.

The current economic crisis has beaten fully our collective. This year, the associations have not received a single euro from promised subsidies that support our already precarious networks, and we foresee deep cuts in the immediate future. Private donors have also vanished, it seems all interest helping the disabled is no longer fashionable. We cannot get loans to address our economic situation because we cannot guarantee their return.

All the associations here, aware of our usefulness for the whole society, urge policymakers to consider the investment in mental health. In this Mental Health Day, we come together to demand the authorities, companies and society in general to keep the support
The Norwegian branch of WAPR was registered as a NGO in 2011, when the national board was moved to Bergen and established here. The professionals in the new board all have comprehensive experiences in the field of psychosocial rehabilitation and recovery, a family member is part of the board and we are working on recruiting members with service user experience.

The board has three central objectives; 1) information in Norway about WAPRs organization, goals and activities; 2) strengthen international collaboration and 3) draw on international rehabilitation and recovery competencies in developing national services, community development and user involved practices.

In spite the recent years with national action plans and increase of funding in mental health services in Norway as well as focusing on deinstitutionalization, there is high use of compulsory treatment in mental health services and also high use of inpatient psychiatric treatment. The national branch will together with the service user organizations be a voice for supporting community based recovery oriented services and for strengthening human rights, user empowerment and social inclusion.

For 2012 we had two specific goals and activities. The first was to organize a national WAPR conference highlighting recovery and what it actually means in our mental health services. The second is to actively recruit Norwegian participation for the WAPR world congress, both in terms of presentations and general participants. The local conference was held 6th of June in Bergen with professor Marianne Farkas as key note speaker. Marit Borg, the WAPR board, informed about WAPRs objectives and the organization as well as about the Milan worlds congress. Norwegian presentations focused on user involvement in mental health research, user involvement in services and service development and a new Norwegian website where both service users, family members and professionals can publish articles in a “Wikipedia way”.

We also promoted the Milan congress and encouraged sending in abstracts. We are very happy to see that Norway will be represented with at least 15 presentations in Milan. And we hope that all of the Norwegian participants on the congress will bring with them home some new international connections to their professional network – and also can contribute in the international community in various ways.

We will organize a second national WAPR conference in June 2013 and will have this as our most important annual event. In the meantime we...
WAPR Indonesia organizes a Symposium on Psychosocial Rehabilitation during the WPA Regional Meeting in Bali Indonesia.

Following its launch as a chapter of the World Association for Psychosocial Rehabilitation, WAPR Indonesia organized a Symposium in collaboration with the Section for Psychiatric Rehabilitation of the World Psychiatric Association, during the WPA Regional Meeting in Bali Indonesia on Sept 14, 2012.

The Symposium was: “Psychosocial Rehabilitation: Concepts and Directions.”

The speakers were:

- Prof. Lourdes L. Ignacio MD: “Towards a Broadened View of Psychosocial Rehabilitation”
- Dr Pandu Setiawan: “New Consensus on Psychosocial Rehabilitation: Indonesian Perspective”
- Dr Afzal Javed: “Involving Patients, Carers and Families in the Treatment Programs: Some Emerging Priorities in Current Psychiatric Practice”
- Dr Tae-Yeon Hwang: “Shared Decision Making as Core Value Of Psychological Rehabilitation”

The Symposium also drew active participation during the open forum, since the papers presented a view of rehabilitation in psychiatric practice beyond those in the hospitals and clinics, involving more the various categories of health, social and rehabilitation workers in the community.