

Original Paper

**Networking with NGOs in the defence of the rights of
the people suffering from mental illness in Latin
America**

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Abstract A group of Argentine mental health professionals had the intention of working with users and relatives non governmental organizations (NGOs) towards the defense of the rights of the mentally ill in Latin America. They started by gathering specific information about the existence of self help and advocacy groups in Argentina. Data bases were analyzed in search for non-profit NGOs working on Mental Health. A hundred and fifty institutions were listed, working on specific fields such as schizophrenia, bipolar disorders, anxiety disorders, suicide, Alzheimer disease, Parkinson disease, alcohol or drug abuse, eating disorders, handicapped people, half-way houses, etc. An institutional analysis showed that the country's socio-economic crisis made it very difficult for them to give continuity and visibility to their actions. The need for an umbrella NGO which could articulate and support their growth, as well as insert them in the international scenario was evident. The possibility of creating such an NGO was explored. The answer was so good, that Contener Foundation was founded. Clear objectives for the Foundation were established, especially focused on education of the professionals and the public, defense of the rights of the mentally ill, research, and networking with NGOs related to mental health.

Key words: advocacy, mental health, networking, non governmental organizations, patients' rights

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INTRODUCTION One of the moral obligations of a society is to take care of the members who suffer. People who are affected by psychosocial and mental disorders are a big problem to public health, so the definition of policies and programs which ensure prevention, care and the rehabilitation of such people is of great importance (Montenegro, 2005).

Human Rights -one of the greatest inventions of our civilization- are instruments which are transcendental for social life. They are an essential tool to avoid human- produced catastrophes. The acknowledgement of human rights was spread through the Constitutions of almost all the States and through the international standards such as the Universal Declaration of Human Rights, issued by the United Nations Organization in 1948, and the subsequent agreements encouraged by this organization on subjects like: civil and political rights and economic, social and cultural rights. Thus, the human rights and the fundamental liberties are conditions of outstanding importance for the achievement of freedom, justice, international peace and individual and group mental health; therefore, they are a key aspect for our specialty. The prestige of our professional associations is undoubtedly better guaranteed when we have at our disposal structures such as Ethics Committees or Human Rights Committees, which promote a permanent improvement of our practices, warning us against different forms of violation or ignorance of human rights in general, as well as of the specific rights of the mentally ill patients. Besides respecting the rights of the patients in their professional practice, it is recommended that psychiatrists work actively to support them. Given the fact that throughout history, the mentally ill have been abused, neglected, and discriminated against, a group of Argentine psychiatrists decided to develop actions to try to improve such condition.

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Individuals who are, or who are perceived to be, mentally ill suffer from a triple handicap: their illness, the stigmatization resulting from their illness, and the complexity of the system developed to serve them. Their illness may be more or less successfully treated by means of revolutionary scientific, socio-economic and public health approaches. However, a far greater handicap than the illness itself is the stigmatization resulting from being labeled mentally ill. This stigmatization leads to prejudging patients' capacities, to interpreting excessively or to diminishing the importance of their views, and to placing mental health concerns at the bottom of any priority list. Although other groups suffering from discrimination have successfully gathered to assert their rights, people living with mental illness have not. The reason may be that mental illness at times makes individuals less effective spokespersons than other citizens for their own concerns. In no way, though, does it diminish the importance or relevance of their concerns. Consequently, many advocacy groups have been formed lately, to fight for the rights of people with mental illness, taking into special consideration cultural diversity.

The strong development of such movements can be traced back to the 1960s, a time of revolutionary processes when the previously mentioned developments of the neurosciences, psychotherapies and psychosocial interventions, as well as new institutional interventions like the integration of psychiatric care within primary health care, began to affect the lives of people living with mental illness. Growing support for the rights of the mentally ill joined other liberation movements –those of women, those with same sex preferences, racial minorities and the poor– which aimed to modify institutional control in the western world. Opinion developed that the long-stay hospital creates conditions that harm patients, creating a depersonalized atmosphere. In-patients were compared to slaves, so alternatives were sought. After all these years, a useful debate now occurs with less extreme viewpoints (Elizur and Minuchin, 1990).

In its classic sense, advocacy means "to call to one's aid or assistance". Among the objectives of advocacy, WHO includes: the promotion of human rights of the persons with mental disorders and of their families, and monitoring the life conditions of people with mental illness and their families. Parity of care with people with other illnesses needs to be assured in all health schemes.

Through use of partnership relationships with Non Governmental Organizations (NGOs), WHO is supporting countries in encouraging development of the very important advocacy sector, especially the consumer/user and family aspects through the crucial establishment of self help and peer support services. In spite of this, the advocate's function in the mental health system has been much misunderstood and maligned. Mental health professionals must recognize the importance of these developments for all aspects of patient care. To ignore or blindly resist the changes emanating from the patients' rights movement will have an adverse effect on the mental health professions and deny patients the assistance of their most constant and powerful allies - mental health professionals. Moreover, mental health workers should make a serious commitment to protect patients' rights and accept responsibility for building more collaborative, less authoritarian relationships with patients. A further complication for the mentally ill is the great complexity and diversity of the mental health support system. Mental health programs represent an evolving multidimensional system with clinical, legal, economic and political ramifications.

A landmark in the history of Latin American Psychiatry has been the Declaration of Caracas, which was produced in 1990 by the Regional Conference on the Restructuring of Psychiatric Care in Latin America, convened in Caracas, Venezuela, by PAHO / WHO Regional Office for the Americas. Such Declaration includes aims such as:

- ♦ the restructuring (of services that) will permit the promotion of alternative service models that are community-based and integrated into social and health care networks;
- ♦ critical review of the dominant and centralizing role played by the mental hospital in mental health service delivery;
- ♦ safeguarding personal dignity and human and civil rights;

- ♦ redrafting national legislation must occur if necessary;
- ♦ training in mental health and psychiatry should use a service model that is based on the community health centre and encourage psychiatric admission in general hospitals.

To contribute towards the fulfilment of these aims, the Latin American Psychiatric Association published in 1998 the Spanish and Portuguese versions of the book *Physicians, Patients, Society*, which was originally published by experts from the Bulgarian Psychiatric Association. The book contains documents by the World Medical Association, World Health Organization, World Psychiatric Association, United Nations and European Council and includes the Madrid Declaration, issued by the World Psychiatric Association and the Ten Basic Principles of Mental Health Care Law, issued by the World Health Organization. The book has been considered reference material for the professional practice of many Spanish-speaking professionals. Guimon (2001) states for example that «In view of the significant impact of public health policy on human rights, the need for a human rights impact assessment is stressed».

Psychiatric Services in developed countries were highly centralized as a result of the massive programme of building psychiatric hospitals. The process of running down and closing these hospitals has resulted in decentralization, with the establishment of community-based services. In many developing countries, the great majority of people with psychiatric conditions are managed in the community, but with very few specialized professionals. In many of these countries, the development of psychiatric services continues to have a low priority despite the high level of chronic disability caused by psychiatric illnesses (Leff, 2001).

Deinstitutionalization has led to the families having responsibilities as carers of their handicapped members (Thompson & Doll, 1982). So patients and their families have become active participants in the processes of prevention, cure and rehabilitation. The creation of self-help and advocacy groups is the most effective tool to implement and develop active lobbying for the defence of the rights of patients and families. The advantage of educating and making alliances with the families lies in the possibility of building community resources, basing interventions on real needs and strengths, and sharing the responsibility of care with the users of the services.

Networking with NGOs working in the field of Mental Health is a first rate strategy from the ethical, political and epistemological point of view to improve the patients' quality of life. Networking involves coordinating actions with groups which share similar objectives:

- ♦ support, guidance and education;
- ♦ each member of the group giving his or her best;
- ♦ reaching the best possible solution to a given problem.

The needs of patients, their families and society as a whole require a multiple approach, including:

- ♦ neuropsychopharmacological
- ♦ psychosocial
- ♦ educational
- ♦ legislative
- ♦ judiciary.

This approach differs from the traditional health care services in that it includes cooperation with multiple NGOs & GOs.

MATERIALS AND METHODS The present Argentine scenario is a direct consequence of the events that took place in the last four decades and it has very many elements in common with the majority of Latin American countries. During the 60's and 70's Argentina was a promising country in which the state actively supported the development of high quality services for the care of people suffering from mental illness by creating services of psychopathology and mental health in general hospitals all over the country, together with community mental health services, therapeutic farms, half way houses and protected workshops. There was an autonomous National

Institute for Mental Health, and a state policy which supported the training of residents within structures that included trainers and supervisors who taught about clinical topics, public health and public policies for mental health to physicians, psychologists, social workers, occupational therapists, psycho-pedagogists, music therapists and other mental health professionals. The high level in the development of psychodynamic and psychosocial conceptions resulted in its becoming a model for other countries in the region, and even Spain. Unfortunately, this was followed by a decade of military dictatorships all over Latin America – specially in Argentina – during which human rights in general were violated, as well as patients' rights, The strong suspicion that these activities supported the so called subversive movements led to a process of closing down such facilities, thus throwing the country back into unfavorable conditions for mental health care. Many outstanding professionals such as Mauricio Goldenberg – PAHO counselor for mental health - E. Pichon Riviere, J. Garcia Badaracco, and Etchegoyen had been key in the development of Argentine psychiatry, but some had to emigrate for political reasons and exported the Argentine model to other countries such as Venezuela, Brazil, Spain and Mexico.

The weak democracies born in the mid 80's continued to support the concentration of richness on a minority of the population, thus leading to the impoverishment of most of the society, which was forced into unemployment and marginalization. Moreover, the 90's brought about the dismantlement of the state, the satanization of welfare state policies and the putting into practice of the economic spill-over theory. It is in such context that the above mentioned Declaration of Caracas for the Restructuring of Psychiatric Care took place, going back into those concepts supported by Kennedy's mental health law in USA, sector psychiatry in France, national health system in UK and Italian anti-psychiatric movement.

An interesting pending subject is to research on the importance of the cost-benefit implementation of prevention in the three levels when compared to the tendency to the biologicistic reductionism which is supported by economic interests.

In the year 2000, it became clear to a group of mental health professionals -through the evidence provided by their personal historical experience in advocate fields and several sources of information- that users and relatives' organizations dealing with Mental Health in Argentina were in need of help. They decided to face the challenge of collaborating to develop an institutional program, as a way to provide the needed help. Their first task was to gather specific information about the existence of self help and advocacy groups in Argentina. Using personal contacts and some data bases, they searched for users' and relatives' organizations working on Mental Health. As a result, a hundred and fifty institutions were listed. Their working fields ranged from psychiatric disorders such as schizophrenia, bipolar disorders, anxiety disorders, suicide, Alzheimer disease, Parkinson disease, alcohol or drug abuse, eating disorders, to handicapped people, or even half-way houses, to mention a few.

It is important to note that at the time this experience started, at the end of the year 2000, Argentina was in a deep socio-economic crisis, which later resulted in a well known default. In these circumstances, it was very difficult for NGOs to give continuity and visibility to their actions, as funding was extremely limited and resources of all kinds were scarce. It was evident that such conditions called for the creation of an umbrella NGO which could articulate and support the growth of the very many existing NGOs, as well as insert them in the bigger international scenario.

The possibility of creating such an NGO was explored and as the response of those NGOs was positive, Contener Foundation was founded. The necessary legal action was undertaken and the profile of the Foundation was designed by its clearly defined objectives:

- ♦ Defend the rights of people living with mental illness and improve legislation;
- ♦ Act against stigma and discrimination against them;

NETWORKING WITH NGOs IN LATIN AMERICA

- ♦ Support the development of advocacy, self help groups and groups of relatives of mentally ill patients, as well as support the creation of new ones;
- ♦ Support half way houses and community dining rooms for children at risk & mentally ill patients;
- ♦ Produce psychoeducational material and train psychoeducators;
- ♦ Teach psychiatrists, non-psychiatrists physicians, other mental health workers, community leaders, the media, patients and their families about mental disorders and modern approaches to treating them;
- ♦ Grant awards to the best media productions aimed at the defence of patients and their families.

During the period December 2001 – December 2002, Contener Foundation was active in the creation of a network of advocacy groups that now covers most of the vast Argentinean territory, and is also present in neighbouring countries. The main objective was working on psychoeducation and the protection of the rights of the mentally ill, which was very much appreciated by both professionals and the public. As a result of such a successful experience, Contener negotiated agreements of cooperation with many national NGOs, and similar institutions in Latin American countries.

The many activities proposed by Contener Foundation in all these years were very well attended, thus achieving an important presence in the field and gaining the recognition of the community. At present, Contener is an important umbrella organization that brings together not only advocacy groups of people who suffer the consequences of specific psychiatric disorders such as schizophrenia, bipolar disorders, OCD, but also other non governmental organizations that work in the field of mental health. To increase its presence and visibility, Contener developed its website – *www.contener.org* – and its Electronic Bulletin, used to regularly spread the news about the activities performed by Contener and its related NGOs among professionals, institutions, patients and relatives.

International visibility was also achieved by participating in the national congresses hosted by the psychiatric associations in Argentina, Chile, Mexico, Uruguay, Brazil, Bolivia and those organized by the Latin American Psychiatric Association (APAL). Symposia and workshops on advocacy, patients' rights, networking with NGOs and many other related topics were presented by Contener.

Moreover, Contener developed an administrative system to supply medicines free of charge - through agreements made with the pharmaceutical industry for the donation of some products- within some important programs, which are supported by two national psychiatric associations which are Member Societies of the World Psychiatric Association (WPA): the Association of Argentinean Psychiatrists (APSA) and the Argentinean Association of Psychiatrists (AAP). When necessary, patients and relatives have received legal advice, in accordance with current regulations, regarding their rights concerning treatment.

Since 2002, the intensive work each year has been rounded off at a National Meeting, which later became International, attended by NGOs, advocacy groups, governmental officers, representatives from the judiciary and the legislative powers, the media, educators, and leaders of different religions. As a result of such meetings, there were proposals for future actions and ideas for new developments. Also, valuable testimonies from people suffering from mental disorders were obtained and taped. Undoubtedly, events of this kind give Contener a high visibility and highlight its importance. Consequently, the Foundation has appeared in several newspaper articles, as well as radio and TV interviews, due to its fight against stigma and discrimination.

Moreover, Contener Foundation edited a book on Bipolar Disorders, written by Profs. Alberto Bertoldi and Roger Montenegro. It is also in the process of launching and distributing the Spanish

version of the *Alliance Program. A resource for patients with schizophrenia, their caregivers and mental health professionals*¹ and it is planning to make new publications about other neuropsychiatric disorders.

Thanks to the funds obtained by Contener, it has been possible to grant preceptorship and partial sponsoring of some community activities like halfway houses, hostels, community dining rooms for children at risk, etc. since 2004.

The Foundation has also developed advocacy activities to raise awareness about neuropsychiatric disorders, and created annual awards:

- ♦ 2004: Contener and the Media. Best media production against stigma and discrimination
- ♦ 2005: Best institutional production in the field of rehabilitation
- ♦ 2006: Best legal action in defence of the rights of the patients.

The number of applicants and presentations made has been steadily increasing. Once the Foundation became solid at home, it started developing relations with other international NGOs. Thus it is now a NAMI MIO Partner Coalition member (National Alliance for the Mentally Ill - Multicultural & International Outreach), an Affiliated Association of the World Federation for Mental Health (WFMH) and the representative in Argentina of the World Association for Psychosocial Rehabilitation (WAPR).

An example of such activities is the 4th National and International Meeting of Contener Foundation, “Rehabilitation and Psychosocial Integration of the Patient”, which took place in Buenos Aires in 2005, during which the World Mental Health Day -an Education Campaign of the WFMH- was celebrated. The main theme was “Mental and Physical Health across the Life Span”. This Meeting was supported and attended by about 150 domestic and foreign Governmental Organizations (GOs) and NGOs.

RESULTS After five years of existence, Contener Foundation has proved to be a successful NGO, which has fulfilled its original objectives through the high level of participation and commitment of patients, relatives and related NGOs, who positively evaluate the previously described experience.

Besides the encouraging opinion by peers, the Foundation has also received positive feedback from the other actors involved: for example, GOs working in the fields of health, welfare, justice, education, security forces, legislation, and the media.

This Argentine experience served as a basis for the birth of a similar NGO in Bolivia (FUNSAME), and it is expected to have a multiplying effect.

DISCUSSION AND CONCLUSIONS The Contener Foundation experience might be a model for other NGOs, but local specific conditions should never be overlooked when trying to put any model into practice. The differences in political, cultural, social and economic conditions will definitely affect the model, and each society should find the one that fits its own conditions in the best manner.

Argentina has suffered the deepest social, political and economic crisis in its history and Contener has highlighted the importance of comprehensive concepts and networking in spite of such a negative scenario. Although the seriousness of this crisis did not exclusively affect Argentina – globalization is a worldwide phenomenon affecting millions of people, and the Argentinean default was unprecedented and its consequences involved many countries - it has had local characteristics which have made it worse: lack of state policies and lack of a genuine

¹ Developed by Prof W. Wolfgang Fleischhacker and Prof Martina Hummer (Innsbruck, Austria). Reviewed by Dr Miguel Bernardo (Barcelona, Spain), Ass Prof Marcelo Cetkovich-Bakmas (Buenos Aires, Argentina) and Ass Prof Tamas Tenyi (Pecz, Hungary).

consensus for the respect of public interests, mixed with high levels of structural corruption and a huge debt.

A number of questions about the role of NGOs in such a context may be posed:

1. *Given the fact that there are GOs which should promote, perform and coordinate the tasks undertaken by NGOs, is it valid for the latter to do them?*

Definitely it is, as GOs are usually paralyzed by normal political changes (pre and post elections periods, for example), and the solidarity actions carried out by NGOs are of utmost importance for those in need, who cannot wait for the right political timing to receive help.

2. *Is it useful for NGOs working in the field of mental health to support, validate and participate of a structure such as the one of Contener?*

Such NGOs have repeatedly expressed their gratefulness for the impulse Contener has given to their initiatives, thus revitalizing them and, somehow, compensating the lack of support within public policies.

3. *How could NGOs networks be recognized by GOs as a priority in public health policies?*

GOs should acknowledge the significance of the actions performed by NGOs, which are inspired by the wish to fulfill the objectives of their institutions, rather than by political speculation or personal narcissism.

4. *Could this successful five year experience be sustained in the long run?*

Mainly by providing a useful service to the community, so that high visibility is achieved, interest aroused and funds obtained. Creativity and permanent presence are key factors.

5. *Why do so many institutions find it difficult to move from their administrative bureaucratic structures into action?*

Bureaucratic structures are identified with hierarchies and standard procedures, but there are some urgent problems which need individual solutions. Bureaucracy and economic constraints are obstacles which can only be overcome by creativity. NGOs can be more specialized and flexible and find answers more effectively.

Contener has demonstrated that there are lots of positive actions to be done despite the above described unfavorable environment, which has brought about the outcry of suffering people, generalized protests and disbelief in politics – no matter what ideology or political party is involved.

Working with NGOs, together with GOs from the fields of justice, health, social welfare and education, among others, and educating psychiatrists and other physicians, as well as the public - including primary, secondary and college students- are promising activities towards a better future. Moreover, learning from NGOs working in other contexts, under different conditions, is very much enriching. Networking with NGOs worldwide could become a first step towards reaching global cooperation. “It is better to light up a small candle than to curse darkness” (Confucius).

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