Advocacy for mental health: roles for consumer and family organizations and governments

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SUMMARY
The World Health Organization urges countries to become more active in advocacy efforts to put mental health on governments’ agendas. Health policy makers, planners and managers, advocacy groups, consumer and family organizations, through their different roles and actions, can move the mental health agenda forward. This paper outlines the importance of the advocacy movement, describes some of the roles and functions of the different groups and identifies some specific actions that can be adopted by Ministries of Health. The mental health advocacy movement has developed over the last 30 years as a means of combating stigma and prejudice against people with mental disorders and improving services. Consumer and family organizations and related NGOs have been able to influence governments on mental health policies and laws and educating the public on social integration of people with mental disorders. Governments can promote the development of a strong mental health advocacy sector without compromising this sector’s independence. For instance, they can publish and distribute a directory of mental health advocacy groups, include them in their mental health activities and help fledgling groups become more established. There are also some advocacy functions that government officials can, and indeed, should perform themselves. Officials in the ministry of health can persuade officials in other branches of government to make mental health more of a priority, support advocacy activities with both general health workers and mental health workers and carry out public information campaigns about mental disorders and how to maintain good mental health. In conclusion, the World Health Organization believes mental health advocacy is one of the pillars to improve mental health care and the human rights of people with mental disorders. It is hoped that the recommendations in this article will help government officials and activists to strengthen national advocacy movements.

Key words: mental health; advocacy; user organizations; family organizations

INTRODUCTION
The World Health Organization’s provides technical assistance to governments to develop policies and programmes to promote mental health care and protect the rights of people with mental disorders (World Health Organization, 2005a). However, governments are unlikely to be able to design and implement adequate mental health policies without the involvement of those who will be most directly affected by these policies. Furthermore, governments on their own often cannot adequately educate the public about mental disorders in order to create the social and cultural conditions necessary to eliminate stigma and discrimination against people with mental disorders. It is for these reasons that World Health Organization is also working to promote the emergence of strong and independent mental health advocacy movements throughout the world. Advocacy efforts towards promoting and protecting the rights of people with mental disorders can educate the general public along with policy makers...
and help create the conditions necessary for positive reform. [Throughout, this paper draws heavily on the World Health Organization publication *Advocacy for Mental Health* (World Health Organization, 2003).]

Mental health advocacy can be performed by several different types of organizations. However, it is especially important that organizations of mental health service users emerge to have a voice in shaping policy and public opinion. Organizations of family members of people with mental disorders, professional organizations and non-governmental organizations working in the field of mental health can also play a vital role in mental health advocacy. This paper will describe the role of mental health advocacy groups and World Health Organization’s recommendations for how governments can promote the development of a strong mental health advocacy sector without compromising this sector’s independence. In addition to helping to strengthen existing advocacy organizations, government officials, especially officials in ministries of health, can themselves take certain valuable mental health advocacy related actions.

**BACKGROUND OF MENTAL HEALTH ADVOCACY**

The mental health advocacy movement has developed over the last 30 years as a means of combating stigma and prejudice against people with mental disorders and improving services (Emmet, 1998; Frese, 1998; Morselli, 2000; Crisp et al., 2005). Because of widespread ignorance and misunderstanding about people with mental disorders, they are often feared and face severe stigmatization and discrimination. Government policies are often reflective of these fears. It is sometimes presumed that government’s primary responsibility with respect to people with mental disorders is to protect the general population from them. Such a perspective is not conducive to promoting access to high-quality treatment or respecting human rights (World Health Organization, 2005b). Furthermore, unlike people with other types of illnesses, people with mental disorders are often presumed to lack the capacity to make their own health care decisions.

Advocacy movements emerged as a response to recognition that people with mental disorders were especially vulnerable to serious human rights violations, especially to involuntary long-term detention in psychiatric institutions. Often, such detention lacks any therapeutic purpose or value (World Health Organization, 2001a). The movement was also dedicated to facilitating changes in society at large, in an effort to break down some of the barriers to social integration experienced by people with mental disorders. Most of the earliest advocacy organizations were created by close family members of people with mental disorders. Subsequently people with mental disorders began to form their own organizations to advocate for their own interests [World Health Organization, 2003 (p. 13)]. Along with influencing the government and educating the public, such self-advocacy groups have the additional benefit of giving its members feelings of empowerment and self-esteem, which in themselves confer mental health benefits (Goering et al., 1998; Wahl, 1999).

In addition to helping governments develop progressive mental health policies and laws, advocacy organizations can play a critical role in their successful implementation. They can also advocate on behalf of individuals facing discrimination, abuse or other injustices. For example, a group working to protect the interests of consumers and families in India called Action for the Mental Illness has been fighting in court to force state level authorities in India to treat people with mental disorders the same way they treat people with physical disorders. They are also actively pushing the national government to create a role for participation of the consumer and family lobbies in revising the country’s essential drugs list (Personal communication, N. Srinivasan, 2005). Finally, they are seeking the legal help of the apex court in India to implement the National Mental Health Programmes. In Mexico, a Mental Health NGO has been advocating for community services since 1980 and has also denounced human rights violations in mental hospitals. In 1999, this organization joined forces with the National Secretary of Health to implement a demonstration area where the mental hospital was transformed in a network of community services. Five years later, the learning from this area was used to develop a national strategy for the improvement of mental health services (Personal communication, V. Torres González, 2004).

Advocacy groups have also proved beneficial by becoming social networks for people with
mental disorders and helping to create economic opportunities for them. For example, in Bulgaria an NGO set up by mental health service users called ‘The Children of Kubrat’ have, in addition to working with the government and other NGOs on policy and service development issues, also found ways to build communities of people with mental disorders. For example, they created an Internet Art Gallery featuring works of their own members and have assisted in starting up art and poetry groups composed of mental health service users (Personal communication, Emil Traev, 2005).

Advocacy organizations can also draw attention to barriers to mental health, such as a lack of mental health services, poor quality care in psychiatric facilities, paternalistic services, a lack of information about treatments, abuse and other human rights violations, and the stigma associated with people with mental disorders (World Health Organization, 2001b). An organization started by mental health service users in Zambia, known as Mhunza has been doing just that since its inception in 2001. Along with highlighting the many problems with the mental health system in Zambia, Mhunza has also been actively involved in drafting a new mental health policy and developing new community-based services (S. Katontoka, address at the WHO International Forum on Mental Health, Human Rights and Legislation, Geneva, Switzerland, 2003).

The absence of strong advocacy movements in much of the world contributes to the persistence of appalling conditions for people with mental disorders as well as their political disempowerment. For this reason, World Health Organization has made mental health advocacy one of the four pillars for their global mental health strategy and recommends that all countries take steps to develop or strengthen their mental health advocacy sector (World Health Organization, 2001c). At the same time, it acknowledges that many of the most important functions of an advocacy movement are best carried out by organizations that are structurally and financially independent of government. Organizations that are closely tied to the government may not be as free as outside groups to lobby for changes in current laws and policies, or to denounce human rights violations. Nonetheless, there are steps that governments can take to help strengthen the mental health advocacy sector without compromising its independence.

### ROLE OF GOVERNMENT IN SUPPORTING ADVOCACY ORGANIZATIONS

One useful function that ministries of health can perform is to act as an information clearinghouse for the different mental health advocacy groups in the country. In this way, they can help people involved in the mental health care system — consumers, their families, etc. — learn about the existence of these groups. They can also help the different groups learn about other groups with similar goals, which can lead to the formation of alliances around particular issues. Specifically, governments can develop a database of consumer groups, family groups and related NGOs, establish a regular flow of information between the ministry of health and these various groups and publish and distribute a directory of mental health advocacy groups. The list of links provided by the New Zealand Mental Health Commission’s Website (http://www.mhc.govt.nz/pages/links.htm) provides a great example of this kind of activity.

Ministries of health can also make sure that representatives of consumer groups, family groups and NGOs are included in their mental health related activities. Representatives of these groups can work on drafting committees for new policies and laws as well as on committees with the authority to evaluate mental health facilities and enforce standards of treatment in these facilities. For example, when South Korea was developing their Mental Health Act in the mid 1990s, a controversy developed over some psychiatrists’ opposition to emphasizing community-based rehabilitation rather than large institutions. However, at public hearings held on this issue a number of users and family members expressed support for community-based care. Largely thanks to their efforts at these hearings, the drafters of the law went ahead with the community-based approach (Personal communication, Dr Tae-Yeon Hwang, 2005). In Chile, advocacy groups also played an important role in building support for the 2000 National Mental Health Plan. They helped policy makers overcome the resistance of some psychiatrists and other mental health professionals to downsize the mental hospitals and to develop community services (Alarcón and Aguilar-Gaxiola, 2000, Minoletti, 2005).

When ministries of health undertake educational initiatives related to mental health — for
example, a campaign to debunk beliefs about the dangerousness of people with mental disorders — they can seek help from advocacy groups. Consumers and family members especially can be very helpful in the preparation of audio-visual materials and implementation of face-to-face activities. Similarly, if ministries of health officials are trying to use the media in order to build public support for respecting the rights of people with mental disorders, family and consumer groups can be very helpful. They can communicate about these issues in ways that are more emotionally resonant than even the most well-meaning mental health professional or official. For example, worker cooperatives composed of people with mental disorders in Verona, Italy, worked with a psychiatric self-help group and the Department of Mental Health in implementing a joint programme against stigma. Initial results from the programme were very encouraging (Burti, 2000). In the UK, several public information campaigns involving professional organizations, advocacy groups and the Department of Health have been able to produce changes in the general population’s attitudes in a period of 5 years, with a small but statistically significant reduction of stigma associated to several mental disorders (Crisp, 2005).

Especially in countries where strong advocacy groups do not yet exist, governments can play a valuable role in helping fledging groups become more established. Once again, in doing so, it’s important that governments remain sensitive to the benefits of a truly independent advocacy movement. One way they can help empower consumer and family groups is by providing them with technical support. Advocacy groups can sometimes benefit from learning about up to date research on mental disorders and treatment options. Ministries of health can also take action to make sure that advocacy groups have up to date information on resources available for mental health in communities and about current mental health policy and legislation. In developing countries without strong consumer or family organizations in particular, governments can help establish a strong advocacy sector by donating funds directly to new organizations. It may also be helpful to provide resources such as a place for meetings and office equipment. In addition, they can help train leaders of advocacy organizations in leadership, management and group-functioning skills. However, if the primary purpose of the advocacy organization is to critique actions of the government and prod them to improve services for and treatment of people with mental disorders, one needs to be very careful about entangling the organization too much with the government.

Examples of this type of support occurred in Andalusia (Spain) 1990 and in Mongolia in 2000. The Andalusian Federation of Family Associations was created in 1990 with support from the government and it has played an important role in mobilizing public opinion in favour of social integration of people with mental disorders, speeding up the implementation of new mental health services and providing social clubs for consumers (Dougoud, 1998) (Personal communication, M. López, 2003). The Mongolia Ministry of Health gave support and a small amount of funding to help a start-up NGO called the Mongolian Mental Health Association. This association is comprised of psychiatrists, volunteers and representatives from other NGOs and has carried out public education activities aimed at reducing stigma and educating the general population on mental health issues (World Health Organization, 2002).

**ADVOCACY FUNCTIONS THAT GOVERNMENT OFFICIALS CAN PERFORM THEMSELVES**

There are also some advocacy functions that government officials can, and indeed, should perform themselves. World Health Organization’s module on Advocacy for Mental Health is intended primarily for officials in national ministries of health. It is presumed that these officials are already interested in mental health policy reform. However, in order to enact a new a policy or law it will usually require cooperation from other parts of the government. The national legislature, the courts, the executive and other ministries — especially the ministry of finance — are all likely to have important roles to play in improving the lives of people with mental disorders (World Health Organization, 2005b). Thus, there can be an important advocacy role for officials in the ministry of health to perform themselves: persuading officials in other branches of government to take mental health and the human rights of those with mental disorders seriously.

Ministry of health officials can initiate programmes to build technical evidence on the pervasiveness of mental disorders, the public health
burden that they pose, and the availability of effective and relatively inexpensive interventions. Such data can be vital in persuading government officials that mental health ought to be a priority and that it is something that can be substantially improved through government action. In addition, ministry of health officials can often directly lobby officials in other parts of the government to make mental health more of a priority. To do so, it is advisable that they first identify themes that are already important to the public and show how improving mental health tie into those themes. For example, in South Africa, the Government has set up a National Crime Prevention Strategy in order to deal with the serious economic and social consequences of violence and crime. As part of this national initiative, the Mental Health Section of the Ministry of Health could begin certain mental health programmes, such as counselling training for general health workers, crisis centres, violence prevention in schools and mother–infant bonding. Previously, politicians and senior health planners had not supported funding these programmes only based on improving the level of mental health (Freeman, 2000).

Ministry of health officials might also be particularly well situated to support advocacy activities with both general health workers and mental health workers. They can help academic institutions emphasize quality of care and consumer satisfaction in training mental health workers. Furthermore, they can prepare material to distribute directly to mental health workers or through their professional organizations emphasizing the need for community mental health care and the importance of respecting the autonomy of mental health consumers. The government can also take steps to help general health workers become aware of the burden of mental disease and become prepared to offer basic mental health care.

The government can also facilitate joint activities with mental health workers and general health workers. As general health workers become better prepared to provide care for people with mental disorders it will become easier for people to receive mental health care in the communities in which they live. This will make it easier for people with mental disorders to maintain their relationships and their economic and social roles in their communities. This, in itself, is good for mental health. Finally, because of their authority and national reach, ministries of health can perform some advocacy activities aimed at the general public. Policy makers can take steps, using the media as well as promotional activities to debunk myths about people with mental disorders and spread basic information about mental disorders and how to maintain good mental health. As well as improving mental health in the general population, such public information campaigns can help reduce stigma against those with serious mental disorders. As discussed above, public information campaigns can benefit from collaboration with independent mental health advocacy groups.

**CONCLUSION**

This paper has briefly discussed some of the reasons that World Health Organization believes mental health advocacy is important for promoting high quality mental health care and the human rights of people with mental disorders. It has also discussed actions that ministries of health can take to promote mental health advocacy and act as advocates themselves for better mental health care and better treatment of people with mental disorders. It is hoped that the recommendations in this article will help government officials and activists working to improve mental health care, understand the importance of advocacy and consider means of strengthening national advocacy movements.

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