

Advocacy in Mental Health: Offering a Voice to the Voiceless

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Respected Chairpersons, Past Presidents of the Indian Association for Social Psychiatry (IASP), Members of IASP, ladies, and gentlemen. It is a great privilege for me to be bestowed with the responsibility of the President of the IASP, and I am extremely grateful to the membership of IASP for the same. It is for the first time that IASP is holding its national conference in Mysore, one of the ancient cities of this country, and I hope this will be a new experience for our members. I have chosen the topic “advocacy in mental health” for the presidential address today.

Advocacy in mental health may be viewed at two levels. One is at the population level involving all the mentally ill people and the mental health of the whole population. The second is advocacy for the individuals with mental illness.

What is Advocacy?

In modern English, advocacy is commonly understood to mean speaking, pleading or interceding for someone else. In its report on patient advocacy, the Royal College of Psychiatrists states that “In relation to people with mental health problems or learning difficulties, it has the rather different meaning of helping people to be heard and ensuring that what they say influences the decisions of the clinical staff.”^[1]

In practice, the word is used to cover a wide range of activities, resulting in the obfuscation of the core concerns^[2] This lack of a clear interpretation has delayed attempts to achieve consensus on what is good practice and how it may be evaluated.^[3] Its meaning might be restricted to those activities carried out within a set of principles by specific individuals employed or volunteering for the purpose. The key characteristics of advocacy are:

- Empowering - The idea is to enable individuals to speak for themselves or if this is not possible, to

ensure that their point of view is acknowledged and understood-allowing them to make informed choices

- Independent - Advocates must be able to express their clients’ views without prejudice
- Inclusive - Everyone should be able to access an advocate, irrespective of any aspect of their personal situation, including their ethnicity, culture, gender, sexual preference or age
- Impartial - Advocates must not judge their clients. They might be the only persons who can represent their clients’ points of view and they must present it as valid and truthful as possible for the person
- Confidential - All information shared between the advocates and their clients is confidential, except where harm is threatened to anyone. Any information given to the advocates will be shared with their client, in all but exceptional circumstances
- Free of cost - Advocacy services must be free to the recipient.^[4]

There is a tendency to describe any form of verbal support given to the individual as advocacy, irrespective of whether the person has even been consulted. The word accumulates meanings, according to the agenda of the person using it. It can be used to support conflicting ideologies and practices with no reference to the views of the people supposedly being represented.^[5] An example is when individuals, whether they be staff, friends or family members, acting as advocates, promote their own preoccupations.^[6]

According to some commentators “it is not the professional deciding what is best, but the genuine attempt to get into the mind of the patient/client, which is the basis of genuine advocacy.”^[7] It is argued that advocacy has a key role to play in mediating the danger of unchecked medical paternalism in psychiatry.^[8]

Why Advocacy?

The central tenet of advocacy in health care is that service users should be enabled to speak up on their own behalf and empowered to take a lead in the decision-making process. The various types of advocacy are held together by the “matrix” of self-advocacy that is, speaking for oneself.^[9]

There are many ways in which advocacy can benefit mental health-it improves the individuals’ understanding of their situation, enables their views to be heard, ensures that they have the opportunity to be partners in their care and increases their autonomy. Advocacy promotes the rights

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of those who suffer discrimination because of their age, disability, sexuality, gender or culture. It has been argued that advocacy also ensures the quality of the care system.^[10]

People with intellectual disabilities, physical impairments, mental disorders and also children and older people often find it difficult to make their voices heard when decisions concerning their lives are made. Their reliance on others and concomitant social isolation can leave them vulnerable to exploitation and abuse. It is in this setting that advocacy is slowly expanding in India and other countries.

Concept of Mental Health Advocacy

The concept of mental health advocacy is relatively new and was initially developed to reduce stigma and discrimination and to promote the human rights of persons with mental disorders. The mental health advocacy includes a variety of different actions aimed at changing the major structural and attitudinal barriers to achieve positive mental health outcomes in populations.^[2]

Over the last three decades, the needs and rights of persons with severe mental disorders have become more visible. Families, and subsequently consumers, developed organizations enabling their voices to be heard. They were joined and supported by various nongovernmental organizations, many mental health workers and their associations and some governments. More recently the concept of advocacy has been broadened to include the needs and rights of persons with mild mental disorders and the mental health needs of the general population.

The advocacy movement has substantially influenced mental health policy and legislation in various countries and is believed to be a major factor in the improvement of services in others. In several places, it is responsible for creating an increased awareness of the role of mental health in the quality of life of populations. In many societies, support networks have been established through advocacy organizations.

Actions typically associated with advocacy include the raising the level of awareness, dissemination of information, education, training, mutual help, counseling, mediating, defending and denouncing.^[2]

Development 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.^[11] 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 for protecting the human rights of persons with mental disorders.^[12] 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 the recognition that people with mental disorders were especially vulnerable to serious human rights violations, like involuntary long-term detention in psychiatric institutions. Often such detention lacks any therapeutic purpose or value.^[13] The movement was also dedicated to facilitate changes in the 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 early advocacy organizations were created by close family members of the people with mental disorders. Subsequently people with mental disorders began to form their own organizations to advocate their own interests. 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 by themselves confer mental health benefits.^[14]

The following categories of organizations are associated with mental health advocacy:

- Consumer groups
- Organization of families and friends of people with mental disorders
- Professional associations
- Nongovernmental organizations working in the field of mental health
- A wide range of mental health associations, including consumers, carers, mental health professionals, technicians, artists, journalists and other people interested in mental health.

Governments and ministries of health in several countries also support and in some cases carry out, advocacy initiatives in favor of mental health and persons with mental disorders.

International organizations like the World Federation for Mental Health, Alzheimer's Disease International and World Fellowship for Schizophrenia and allied disorders have a strong commitment to mental health advocacy.

The Nature of Advocacy and its Practitioners

The mental health advocate may be one of a range of individuals, the person themselves (the self-advocate), a friend or family member, someone with specific training in advocacy or a lawyer. Wolfensberger promoted the concept of the "citizen advocate," a volunteer who takes on the role as part of their sense of responsibility as a member of society

who would befriend their protégé over months or years.^[10] There are others who argue for “peer advocacy” where the supporter has used similar services and can employ this experience to understand the individual better^[7] Advocacy can also be carried out by people working together in a group.

Independent Mental Health Advocates

Advocacy demands time and dedication, and it is increasingly common for advocates to be paid for their services. These advocates are usually professional, salaried, trained and subject to specific standards of practice. They work with each client for a limited period of time and for a particular purpose. They do not offer prolonged contact or befriending.

Independent Mental Capacity Advocates

Enabling someone to express their own views clearly is less possible if their mental capacity is diminished. Independent mental capacity advocates, because of the specific nature of their clients in most cases, will often have to rely on their own judgment. Where the individual is unable to communicate and has left no evidence of what their preferences would have been, the advocate has to attempt to understand and ensure that the staff have taken into account, what they believe their client would have wanted. The decision maker has then to make a decision in the best interest of the individual. Where there is an advance directive, the advocate has to respect it.

The Purpose of Advocacy

Advocates may act for the individual or for the group. Their aim may perhaps be to improve care, to protect safety or rights, to demand further resources or to influence policy. At the individual clinical level, the client may discuss with the advocate their own case, their participation within this and their ambitions for themselves. At the group level, advocates may work with others to effect changes to local or national services or to represent client groups in arguing for national policy reforms.^[4]

The Role of Healthcare Staff

The health care staff have two roles. One is to assist the independent advocate and the second is the advocacy role that they themselves take on.

Promoting advocacy with policy makers and planners

World Health Organization proposes two steps approach to promoting advocacy with policy makers and planners.^[2]

Step I: Build technical evidence

Step II: Implement political strategies.

The main tasks in Step I are the following:

Determine the magnitude of the problem of mental disorders

Globally more data on the magnitude of mental disorders are becoming available which includes useful information on the prevalence of mental disorders and mental health risk factors. The burden of mental disorders that is, disability adjusted life years, is another important measure of the magnitude of mental disorders. It is useful to supplement the data on the current magnitude of mental disorders with information on the current demand for services.

Determine the cost of mental disorders

Studies on the burden of mental disorders can be translated into economic terms. Thus, the problem is presented in a concrete manner for policy makers and planners.

Identify effective mental health interventions

Ministries of health should establish alliances with universities and other research centers in order to evaluate the effectiveness of mental health interventions in their countries or regions.

Select cost-effective interventions

The most influential technical evidence for policy makers and planners comes from studies on cost effectiveness, which provide exact information on health benefits obtainable from certain amount of money.

Step II: Regardless of the technical evidence, many decisions relating to health are made for political reasons. Policymakers often make decisions on the basis of their public image, existing power struggles and support from the people. For this reason, it is useful to identify the motives that can lead policy makers to give priority to mental health.

Identify themes ranking high in public opinion

Every society has some themes that are considered priorities by the majority of the population at a particular moment. Policy makers generally become more involved with these themes, which represent the people's principal needs, than with others. If the themes are properly dealt with, the public image of policy makers can improve, and more popular support can be obtained. The professionals responsible for mental health in ministries of health should propose mental health strategies and interventions that can help to solve some of these priority problems. The two examples of the problem themes are suicide and substance abuse among the young.

Demonstrate that the themes can be successful

Policymakers need to know that commitment to a particular theme will produce concrete positive results. For this reason, mental health professionals should present their proposals with a defined budget and expected results that can be quantified and made visible to the general public.

Establish empowering alliances between mental health advocates

The policy makers will be more inclined to support mental health if they are approached by large alliances of stakeholders, all advocating in the same direction. The mental health professionals should help to build alliances that involve a range of mental health advocates. This increases power and capacity to campaign for particular mental health issues with members of legislative and the executive branch of the government.

The role of mass media in advocacy

The mass media can be used to inform the public, to persuade or motivate individuals to change their attitudes and to advocate for changes in the social, structural and economic factors that influence mental health.^[2]

The informing or educational role attempts to create awareness, knowledge and understanding of mental health issues in the community or in major subgroups of the community.

The persuading or motivating role attempts to alter individual's attitudes and/or to encourage certain behaviors or actions through emotional arousal techniques. An important activity would be to reduce the stigma associated with mental disorders and to encourage individuals to adopt behaviors supportive of persons with mental disorders and disabilities.

The advocacy role aims to achieve changes in the sociopolitical environment which would improve mental health. This could be done by re-framing public debate so as to increase public support for more effective policies in the field of mental health. This might also encourage community groups working on mental health to participate actively in the political process.

The three most common methods for using the media to address mental health issues involve advertisement, publicity and education through entertainment.^[2]

Advertisement can be useful for creating or increasing awareness about the value of mental health in people's everyday lives and about the existence of mental health services. It is also useful for the neutralizing misconception about people with mental disorders and negative factors that influence mental health in general. Although this approach is expensive, it is valuable for reaching large numbers of people in a short period.

Publicity involves the creation of news in order to attract the attention of the public to specific aspects of mental health and to promote their involvement in mental health activities. However, with this method one has less control over the messages and their exposure.

Education through entertainment involves the placement of educational messages on mental health or other social

matters in the entertainment media in order to promote changes in knowledge, attitudes, beliefs and behaviors. This may be achieved for example through television and radio, songs, music, comics, and novels. This method has been successfully used to promote social and health issues in developed and developing countries. It can make a valuable contribution to mental health advocacy.

Advocacy in India

The advocacy movement in India is gaining momentum slowly, especially during the past one decade. The mental health professionals have been the main group promoting mental health in India. Recently, consumer groups, family groups, and nongovernmental organizations have also started to function. Certain groups like action for the mental illness are also active. They have been fighting in court to force state level authorities in India to treat people with mental disorders in the same way they treat people with physical disorders. They are also actively trying to persuade the central government to create a role for the participation of consumers and family groups in revising the country's essential drugs list. They are seeking the legal help of the apex court in India to implement the National Mental Health Programme.^[15] The influence of the consumer and family organizations is reflected in the draft of the new mental health care bill. The provision for nominated representative in the new Mental health care bill is a step towards the individual advocacy in the country.

The Role of the Indian Association for Social Psychiatry

The IASP established in 1984 can play a vital role in developing mental health advocacy in India. The association itself can act as an advocacy group to improve the mental health care, mental health policy and mental health legislation in the country. The association can also work to improve the psychiatry training of medical students at the undergraduate and postgraduate levels, psychiatry training of nursing students and training of other mental health professionals like clinical psychologists and psychiatric social workers. The association can empower the advocacy groups by providing them with information, training, and funding. The association can organize seminars, workshops, etc., on mental health advocacy and patient's rights. Finally, the association can act as a bridge between mental health professionals and consumer groups when conflicts arise between them.

Dilemmas and Controversies

The degree of consumer control in mental health care is a very controversial issue. The aggressive campaigning by a few NGOs has generated resentment among the mental health professionals. Hence, there should be a healthy balance between advocacy and campaigning. Ideally the health planners should give due consideration

to the concerns of consumer groups while planning, designing and implementing the outpatient, inpatient and rehabilitation services. Unfortunately, the planners in our country have not yet realized the importance of these concerns. At present, mental health is a low priority sector for the health planners. Advocacy groups should campaign for more equitable distribution of funds in the health sector. The health planners should assign an appropriate role for volunteers and NGOs in the implementation of mental health programs. There should be provision for payment to the mental health advocates.

Important human rights issues are involved in compulsory admission, seclusion and restraints and covert medication. We have to debate whether they are essential for the care of the mentally ill or whether other alternative solutions are available. Informed consent and partnership in decision making also call for a broader debate.

Conclusion

The advocacy movements have substantially influenced mental health policy and legislation in countries and have contributed to the improvement of mental health services. India is at the threshold of a strong advocacy movement by groups of consumers and family members. It is, therefore, essential that mental health professionals remain as active partners in this movement. Some of the psychiatrists may be worried about the destructive, ideology-driven power of some advocacy movements. Some may be suspicious and sometimes overtly hostile towards advocacy and patient empowerment.^[16] However we, the clinicians, should not form defensive bastions against patient power and should practice in the best interest of our patients.

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