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**Authors**

Pandya, Anand

Saks, Elyn

Jeste, Dilip V

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# Advocacy, Self-Help, and Client-Operated Services

Anand Pandya<sup>1</sup>  
Elyn Saks<sup>2</sup>  
Dilip V. Jeste<sup>3</sup>

<sup>1</sup>Department of Psychiatry and Behavioral Neurosciences, University of Southern California, Los Angeles, CA, USA

<sup>2</sup>University of Southern California Gould School of Law, Los Angeles, CA, USA

<sup>3</sup>Department of Psychiatry and Neurosciences, University of California, San Diego, La Jolla, CA, USA

## Introduction

Mental health advocacy, self-help services for psychiatric disorders, and client-operated services represent three distinct concepts with organizations and individuals engaging in one, two, or all three activities at the same time. Collectively they represent a relatively new and powerful force that has profoundly altered the experience of living with mental illness for many individuals. *Advocacy* can be defined as the process by which a group or an individual attempts to influence public policy and public attitudes. *Self-help services* for mental illness include services designed to enable individuals living with mental illness or their family members to help others in a similar situation to overcome the challenges created by mental illness. *Client-operated services* will be used in this chapter to refer to services that are provided (and presumably shaped to some extent) by individuals living with mental illness. These services may also be referred to as being “consumer-operated”; however, individuals living with mental illness appear to prefer the terms “client” or “patient” for self-identification (Sharma et al., 2000; Covell et al., 2007). Referring to individuals living with mental illness as the adjectival form of their diagnosis may be considered dehumanizing, hence this chapter will not refer to individuals as “schizophrenics” or “borderlines.” Other common terms of self-identification for individuals living with mental illness include “ex-patients” and “survivors” (a reference not to surviving a mental illness but to surviving psychiatric treatment), both of which are associated with the anti-psychiatry movement (Emerick, 2006).

## Advocacy

Although some physicians such as Phillipe Pinel and Benjamin Rush were reformers within the developing medical

treatment system for mental illness, mental health advocacy can be traced further back to individuals outside the system such as Daniel Defoe, who highlighted the abusive conditions in mental institutions of his time (McCandless, 1978), or individuals who experienced the system first as a patient, such as Jean-Baptiste Pussin, who pioneered many of the humane innovations that Phillipe Pinel made famous (Schuster et al., 2011). Similarly, in the United States, some of the most influential voices for more humane treatment for individuals with mental illness came from outside the mental healthcare system, as in the case of Dorothea Dix, who advocated for government-funded asylums (Parry, 2006), and Albert Deutsch, who highlighted the deplorable conditions in state hospitals (Weiss, 2011), or by clients such as Clifford Beers, one of the founders of the mental hygiene movement (Parry, 2010), and Elizabeth Packard, who fought against misogynistic commitment laws (Sapinsley, 1991), or their family members such as Pete Earley, who raised awareness of the shift from treatment to punishment after deinstitutionalization as many clients are incarcerated rather than hospitalized (Earley, 2007). The two most prominent advocacy organizations in the United States have been Mental Health America (MHA) and the National Alliance on Mental Illness (NAMI), formerly known as the National Alliance for the Mentally Ill. MHA traces its roots back to the Mental Hygiene Movement that Clifford Beers founded in 1909 and NAMI was founded by parents of individuals with serious mental illness (primarily schizophrenia) in 1979. Both organizations expanded from original visions by clients or families to include clients, families, and providers. MHA has also expanded into direct service provision and various local MHA organizations receive government funding

for programs such as LIFENET, the mental health hotline in New York, and the Village (Long Beach, California), a nationally recognized integrated service model. Similarly, NAMI has received local funding to provide psychoeducational programs and federal funding for the STAR Center that provides technical assistance and support for consumer-operated services. Such services may blur the line between advocacy organizations and the mental health system which they seek to improve.

Nonetheless, advocacy organizations have had a tremendous influence on the national dialogue around mental illness. They have conducted systematic and critical assessments of the state mental health infrastructure throughout the United States (NAMI, 2006; Aron et al., 2009) and have served as important champions for mental health parity (Flynn & Hall, 1997), with legislation mandating equal health insurance coverage for psychiatric and nonpsychiatric conditions.

Advocacy (Table 98–1) can occur through different means no less than through different groups. Organizations can lobby, bring law suits, write amicus briefs, and provide education.

In addition to calls for a public investment in better treatment, as in the parity case, some mental health advocacy organizations have focused on increasing the investment in psychiatric research. Advocacy organizations have worked to expand or at least preserve funding for psychiatric research. There is also a movement to include clients as part of the investigative team conducting research, in addition to an increasing focus on research on issues that clients most care about and attending to their own ideas about a research question. In other words, the research may be client driven: what do clients care about? What do they want to know? Over a dozen advocacy organizations are part of the Alliance for Research Progress of the National Institute of Mental Health (NIMH). However, not all advocacy efforts to support mental health research have been uniformly supportive

of NIMH. The Treatment Advocacy Center (TAC) and NAMI have, at times, criticized NIMH for failing to prioritize the severe mental disorders (schizophrenia, bipolar disorder, severe depression, obsessive–compulsive disorder, panic disorder, and autism) that carry the heaviest burden of morbidity and mortality. In 1981, recognizing the limitations of federal-funded research on mental illness, NAMI, MHA, and the National Depressive and Manic Depressive Association (now known as the Depression Bipolar Support Alliance, DBSA) developed an independent organization focusing exclusively on research. Originally called the American Schizophrenia Foundation and now known as the Brain and Behavioral Foundation, this organization is often known as NARSAD, an acronym for National Alliance for Research on Schizophrenia and Affective Disorders. NARSAD has funded over \$300 million in research grants, developing a strategy that complements the research funding from NIMH through its greater focus on young investigators. Despite its historical relationship with NAMI, MHA, and DBSA and the impact of its fundraising efforts on mental health awareness, NARSAD is not an advocacy organization because it is not focused on changing public policy or public attitudes. Rather, it is a charitable foundation that has raised funds from private corporate and individual donors to fund research directly. By contrast, One Mind for Research, a new not-for-profit organization focused on research for all brain disorders (including nonpsychiatric neurological disorders) can be considered to have a quasi-advocacy approach to research since it seeks to develop public–private partnerships to leverage funding from the government and the pharmaceutical industry.

Although psychiatrists and psychologists such as William James and Adolf Meyer were among the charter members of Clifford Beers’ original mental health advocacy organization in 1908 (Alexander & Selesnick, 1966), all of the mental health advocacy organizations discussed so far in this chapter have been primarily considered organizations

**Table 98–1** Advocacy

Roles	<p><i>Professionals:</i> Best qualified to present relevant science but may be perceived as a vested interest</p> <p><i>Family members:</i> Able to provide personal perspective; can be relatively effective when mobilized in large numbers through organized campaigns</p> <p><i>Clients:</i> Best able to provide personal perspective but organizations within the consumer movement are not always organized to present a uniform message through large scale organized campaigns</p> <p><i>Unions:</i> Usually well organized and experienced in legislative advocacy but may be less familiar with the relevant science and may be perceived as a vested interest</p>
Aims	<p>Preserve or expand funding for mental healthcare in the public mental health system, in correctional settings, or in the private sector (through regulations such as mental health parity)</p> <p>Changes in commitment laws or mental health regulations to serve better those with mental illness or to ensure greater preservation of clients’ rights/autonomy</p> <p>Preserve or expand funding for psychiatric research</p> <p>Alter the priorities for psychiatric research</p> <p>Change in criminal law or in correctional settings so as to provide more protections for individuals with mental illness</p>
Effective techniques	<p>Succinct personal stories</p> <p>Face-to-face is preferable to telephone, which is preferable to letters, which are preferable to e-mails</p> <p>Schedule face-to-face meetings in advance and clarify whether you will be meeting with a staff person or the legislator/administrator themselves</p> <p>Follow up meetings with a letter</p> <p>Ask for specific action (e.g., voting on a specific bill number)</p>

of clients and/or family members. However, professional organizations such as the American Psychiatric Association (APA) and other organizations of healthcare providers such as the National Council for Behavioral Health and the National Association of State Mental Health Program Directors can play a critical role in mental health advocacy. With an annual budget that exceeds those of NAMI and MHA combined (APA, 2013) and representation within the American Medical Association (AMA), the APA is well positioned to influence the national political discourse around mental illness. However, it is important to note that the APA and client/family advocacy organizations have overlapping but distinct agendas. Although the APA, AMA, NAMI, and MHA have collaborated closely within the Coalition for Fairness in Mental Illness Coverage to advocate for federal mental health parity legislation (Wellstone, 2001), the APA has demonstrated a greater interest in the scope of practice for psychologists (APA, 2011) whereas client and family advocacy organizations have been more vocal about their support for housing for individuals with mental illness (NAMI, 2013). At times these natural allies will take opposite positions on proposed legislation, as was the case in 2013 when the South Carolina Medical Association and the South Carolina Hospital Association opposed legislation supported by NAMI South Carolina that was intended to make providers more responsive to requests for information about their ill relatives (South Carolina Medical Association, 2013). Effective advocacy requires the capacity to maintain working relationships with potential future allies despite such disagreements on individual issues. In some cases, however, advocacy organizations have fundamentally divergent views on how to achieve the common goal to improve the lives of individuals with mental illness. For example, TAC has been a strong advocate for outpatient commitment laws so that paternalistic psychiatric care can be provided to those who are too impaired to understand their need for treatment. By contrast, the Judge David L. Bazelon Center for Mental Health Law focuses on protecting and advancing the rights of those with mental illness. Both of these organizations work within a common frame that recognizes that many people benefit from psychiatric care yet are likely to disagree about how to improve the system. Even less consensus is likely between TAC and the “Consumer/Survivor/Ex-Patient Movement” that may reject the medical model of mental illness. Organizations within this movement, such as MindFreedom International, in turn may differ from Scientology-related organizations such as the Citizens Commission on Human Rights (CCHR) in that many individuals who identify as consumers, survivors, or ex-patients may still recognize voluntary psychiatric medications as a valid treatment choice for some individuals (Cohen, 2005). By contrast, the CCHR promotes a view that links psychiatry to apartheid, the holocaust, and the Columbine school shooting (Mieszkowski, 2005).

In addition to these organizations, advocacy for government action on psychiatric issues has included a variety of other allies. For example, healthcare industry unions that represent workers in psychiatric facilities may be logical partners when budget cuts threaten ongoing mental health services, and a variety of organizations focused on homelessness or invested in the construction industry may become natural

allies around increasing housing for individuals with mental illness. The purpose of coalitions in political activism is not merely to increase the manpower and resources available to advocate on a specific issue. Diverse groups provide diverse capacities of persuasion. While professionals may be considered authoritative within their realm, unions and representatives of healthcare industry groups may be better prepared with economic arguments. To the extent that professionals, healthcare industry groups, and unions are all perceived as biased by their economic interests, clients and families may prove especially powerful in advocacy efforts. With careful selection of articulate and compelling personal narratives, clients and families can make a powerful case around an otherwise dry governmental policy. However, the ability to edit the emotional stories around mental illness into brief and effective “elevator speeches” is a specialized skillset that may require planning and practice. Some advocacy organizations such as NAMI offer training to refine such advocacy techniques (Pandya, 2012). Similarly, psychiatrists may benefit from systematic training to appreciate the difference between making a scientific argument and making a persuasive case for political change. Such programs are offered by the APA at both the district branch (local) and national levels.

Although advocating for governmental action can occur through a variety of mechanisms, some techniques have proven to be more influential than others. Face-to-face meetings generally are more effective than letters, and personalized letters are more effective than mass letters that use identical language. In general, techniques that represent a greater investment on the part of the advocate elicit greater attention on behalf of the governmental official. However, when actually speaking to a governmental official, it is important to recognize the high demands on their time and therefore the power of personal stories needs to be balanced against the value of brevity. Advocates are more effective if they practice how to make their case in a variety of brief formats (e.g., a 30-second version, a 1-minute version, and a 5-minute version) so that they are prepared to cover their most important points even if the official needs to cut the meeting short. Advocates should also be well versed in specific actions that they want from governmental officials. This could be support for a specific bill or executive order. Finally, it is of value to follow up in-person meetings with a thank-you letter that reiterates the action that is being requested.

Effective mental health advocacy also requires an awareness of the separate functions of state, local, and federal governments. *State governments* have traditionally operated the psychiatric hospitals that were responsible for the care of individuals with chronic mental illness. While the federal government is responsible for an increasing fraction of all healthcare costs since the initiation of Medicare and through the implementation of the Affordable Care Act of 2010, the federal government has limited its responsibility for individuals who require chronic care through a variety of regulations, including the Institutions for Mental Disease (IMD) exclusion, which does not allow Medicaid to cover most facilities that are primarily intended for the care of individuals with mental illness. As a result, states often remain the safety net for people with mental illness who require inpatient or residential care. States also are usually responsible for prisons where a majority of felons are incarcerated. *Localities* are

responsible for jails where individuals are usually incarcerated for shorter periods of time. Localities, especially larger cities, also often take responsibility for services for the homeless. Aside from a few states such as New York and Maryland that have state-run psychiatric research institutions, most advocacy for mental health research is focused on the *federal government* since the National Institutes of Health and other agencies under the Department of Health and Human Services are the largest funders in this arena.

Aside from direct efforts to influence governmental priorities, advocacy can include attempts to influence public opinion more broadly. During the early part of the twentieth century, the mental hygiene movement promoted primary prevention by discouraging unhealthy behaviors in the general public. Such public health initiatives are less prominent than anti-stigma projects in current mental health advocacy organizations such as NAMI and MHA. Stigma, commonly measured by social distance (Jorm & Oh, 2009), has been demonstrated to have a variety of negative impacts on individuals with mental illness (Thorncroft et al., 2009) and therefore combating stigma would logically rank near the top of the mental health advocacy agenda along with the availability of treatment and the development of cures.

Anti-stigma activities can be divided into three categories: protests, education, and contact with individuals living with mental illness (Corrigan et al., 2010) (Table 98–2). *Protest* efforts by groups such as the National Stigma Clearinghouse and StigmaBusters have used telephone calls, letters, and even the threat of boycotts to reduce the negative or belittling portrayal of mental illness in the mass media and to discourage the use of derogatory language around mental illness. *Education* is a less reactive anti-stigma strategy and includes programs targeting members of the criminal justice system (Mental Health Association in New Jersey, 2013), school children (Wahl et al., 2011), and even mental health providers (Mohr et al., 2000). To inform educational efforts, studies have been conducted to assess current attitudes and knowledge about mental illness in the general public (NAMI, 2008; Harris Initiative, 2009). One of the most common foci for anti-stigma campaigns is the medical nature of mental illnesses, and this may be related to the general increase in the public awareness that mental disorders have a neurobiological basis (Pescosolido et al., 2010). With this shift, there has been a greater awareness of the need for treatment by professionals but a biological understanding of mental illness did not appear to decrease stigma. This has led some to focus on the relationship between stigma and the public’s concern about violence perpetrated by individuals with mental illness (Torrey, 2011). Thus, advocates seeking to address stigma

must develop strategies to address high-profile shootings by individuals believed to have serious mental illness, such as the 2011 Tucson rampage and the 2007 Virginia Tech massacre. One such strategy used by advocacy organizations after the 2012 Sandy Hook Elementary School shooting has been to emphasize the need for better access to treatment (Peters, 2013). However, there is little consensus about what educational strategy is most effective to proactively combat stigma.

Aside from protesting about inaccurate, negative portrayals of mental illness and psychoeducation, the third major approach to combating stigma is through *contact with people who have mental illness*. Since stigma is often measured by social distance, there is an intuitive appeal to an approach that builds empathy through a sense of connection with clients and their families. This approach is consistent with research showing that interpersonal contact can increase positive attitudes towards another stigmatized group, gay men (Pandya, 2012). Such contact need not be personal. The lived experience of mental illness has been conveyed poignantly through critically acclaimed autobiographical books (Jamison, 1997; Saks, 2007) and when celebrities and other public figures disclose their personal or family experiences with mental illness (Dukakis & Tye, 2007; Shanahan & Goldstein, 2013). Advocacy organizations have used the power of first-person narratives on a more intimate scale by instructing clients and their family members on how to communicate their experiences effectively when speaking to a diverse group of individuals. Such programs have been shown to be effective in improving mental health literacy and reducing stigma and are also notable for their empowering effect on the speakers (Pandya, 2012).

### Peer/Family Support Models

Although it may seem obvious to some that individuals who have overcome similar challenges are uniquely qualified to understand and provide relevant help to those with a similar condition, the development of self-help models within psychiatry is relatively new (Table 98–3). Some of the slowness in adapting this model may be related to the psychoanalytic tradition of abstinence, which values minimizing self-disclosures by the analyst. Hence it is not surprising that peer-support services for individuals with mental illness were first adapted in parallel organizations outside the realm of formal psychiatric services. The archetypal program of this type, Alcoholics Anonymous (AA), was founded in 1935 and is now available throughout the United States and in many other countries. With its meetings often located outside hospitals and clinics in venues such as churches and community centers AA does not take a position on whether alcoholism

**Table 98–2** Anti-Stigma Techniques

	Protest Stigmatizing Content	Psychoeducation	Contact with People Who Have Mental Illness
Examples	Letters or telephone calls protesting negative media portrayals Boycotting companies that do not respond to letters or telephone calls	Public health campaigns; via television, radio, print media, billboards, etc. Science journalism	Outreach programs such as NAMI In Our Own Voice Indirect contact when an individual “comes out” about their mental illness in the mass media

**Table 98–3** Selected Self-Help Programs

Program	Structure	Target Diagnoses/Populations	Evidence/Comments
<i>For Clients</i>			
Wellness Recovery Action Plan	Course	Individuals with mental illness	Single randomized controlled study (Cook et al., 2012)
NAMI Peer-to-Peer	Course	Individuals with serious mental illness	Large cohort study without control (Lucksted et al., 2009)
Recovery International	Structured support group	Individuals with psychiatric problems	Large retrospective survey comparing recent members with group leaders; used cognitive techniques to control behavior (Galanter, 1988)
Alcoholics Anonymous	Support group	Individuals with alcoholism	Equivocal based on meta-analysis (Ferri et al., 2006); spiritually based 12-step model
Depression and Bipolar Support Alliance	Support group	Individuals with mood disorders	
NAMI Connections	Support group	Adults with serious mental illness	
Emotions Anonymous	Support group	Individuals with emotional difficulties	Spiritually based 12-step model
<i>For Friends and Family</i>			
NAMI Family-to-Family	Course	Family members of individuals with serious mental illnesses	Single randomized controlled trial (Dixon et al., 2011); NAMI also provides ongoing support groups
NAMI Basics	Course	Family members with children or adolescents with serious mental illness	Small cohort study without control (Brister et al., 2008)
Al-Anon Family Groups	Support group	Friends and families of problem drinkers	Spiritually based
Alateen	Support group	Young persons affected by someone else's drinking	Spiritually based
Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD): Parent to Parent	Course	Parents of children with ADD	CHADD also provides ongoing support groups

is a disease and instead focuses on spirituality as the path to overcome this addiction. Although empirical studies on the effectiveness of AA have not yielded a consensus on the effectiveness of the program, its widespread acceptance by thousands of individuals speaks to the widespread demand for a nonmedical approach to this condition. Inevitably, given the popularity of the AA model, there has been some degree of convergence between AA and the nonmedical model of AA. Treatment centers such as Hazelden follow the principles of AA and many referrals to AA are initiated by treatment providers.

Since the founding of AA, many other organizations have developed peer support programs for individuals living with other mental illnesses. Some, such as Emotions Anonymous, were directly modeled on the 12 steps of AA. Organizations that currently provide peer support services include Recovery International, the Copeland Center's Wellness Recovery Action Plan (WRAP) program, DBSA, NAMI's Peer-to-Peer and NAMI's Connections programs. These programs have been shown to provide both subjective benefit (Lucksted et al., 2009) and also objective improvements including reductions in hospitalizations (Solomon, 2004; Cook et al., 2012). In some cases, such as WRAP and NAMI Peer-to-Peer, the support services are structured as educational curricula designed to teach coping strategies.

Similar structured educational curricula have been designed for family members coping with the psychiatric illness of a relative and, as with the peer services, the family course has been shown to lead to both subjective benefit and objective improvements (Marcus et al., 2013). Given the low availability of professional-led family psychoeducation for serious mental illness despite a sizable body of literature suggesting its therapeutic value (Lucksted et al., 2012), courses such as Family-to-Family fill an important gap.

In addition to these courses and meetings that require a critical mass of individuals to be able to meet in some form at the same time, bibliotherapy, the therapeutic effect of reading, offers a self-help modality that an individual can use privately and at one's own pace. Bibliotherapy can be self-guided, through the use of self-help manuals, or can be directed by peers (such as in reading groups) or by professionals. Although much of the bibliotherapy literature examines the effect of some form of self-help material, bibliotherapy can also include works of fiction or poetry, which individuals find helpful in their struggle with mental illness. Bibliotherapy has been shown to have a significant benefit in the treatment of a variety of psychiatric disorders, including panic disorder (Fanner & Urquhart, 2008) and major depression (Gregory et al., 2004).

## Client-Operated Services

Peer counselors employed within the medical treatment industry can provide a form of peer support in this more traditional setting (Solomon, 2004). However, programs that have been designed and developed by clients have permitted the development of important models for peer-oriented services. One of the most influential models has been the clubhouse model for psychosocial rehabilitation that grew out of Fountain House in New York City. Founded in the 1940s by clients discharged from state psychiatric hospitals, Fountain House consists of a community of members with serious mental illness. It provides a broad range of programs to help its members develop both social supports and vocational capacities. The Fountain House model focuses on areas of strength rather than areas of deficits and its philosophy provides for four basic rights to all members: a right to a place to come, a right to meaningful relationships, a right to meaningful work, and a right to a place to return to. Over 400 psychosocial rehabilitation clubhouses have been founded worldwide, although in some instances these clubhouses have merged client-operated services with more traditional treatment models.

## Conclusion

Advocacy refers to the process by which a group or an individual attempts to influence public policy and public attitudes. Some of the most influential advocacy for more humane treatment for people with mental illnesses has come from clients or their family members or physicians taking care of the patients, or even those outside the mental healthcare system. The two most prominent advocacy organizations in the United States have been Mental Health America (MHA) and the National Alliance on Mental Illness (NAMI). These and other organizations and also numerous individuals have sought to influence the public and the government to focus on persons with mental illnesses. These efforts have ranged from assessment of mental healthcare infrastructure at state and federal levels, seeking support for research funding, anti-stigma campaigns, self-help programs, peer/family support models, and client-operated services to provide education and support in parallel to the professional services available within the traditional mental health system. The therapeutic value of these services and the political power of mental health clients and their family members have made significant difference in the lives of many people with mental illnesses. Of course, we have a long way to go before true parity for mental healthcare is achieved. Nonetheless, we have made major gains in this arena during the past two decades through collaborations among different stakeholder groups. We can accomplish even more. The future is bright.

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