Position Statement 21: Rights of Persons with Mental Health and Substance Use Conditions

Policy Position:

Mental Health America is committed to the principles of human and civil rights inherent in the concept of equal justice under the law. This includes rights of persons with mental health and substance use conditions relating to benefits and service delivery, preservation of liberty and personal autonomy, presumption of competency, freedom from seclusion and restraints, protection of privacy, as well as specific consumer needs for employment, housing, benefits, consumer-driven mental health systems, self-help and peer support services, and ending discrimination. This also includes adherence to the Americans with Disabilities Act, the Individuals with Disabilities Education Act (IDEA), the Rehabilitation Services Act, the Fair Housing Act, and other legislation that protects the rights of citizens recovering from mental illnesses. The following statement, concerning rights of individuals affected by mental health and substance use conditions, derives from the principles of choice, empowerment and self-determination and advocates the end of discrimination toward and abuse of people with mental health and substance use conditions.

Background:

Equal justice under the law is a fundamental concept in American jurisprudence. Yet persons with mental health and substance use conditions are often denied equal justice. Too often, discriminatory practices proceed from the misconception that people who are receiving mental health treatment are incapable of responsibly exercising the rights of citizenship. Most importantly, the decision to institutionalize people or treat them against their will may be based upon the assumption that resisting treatment recommendations is evidence that one is incapable of making a responsible independent judgment about accepting or refusing treatment. This logic ignores the principle that a person is competent unless legally proven otherwise. While major strides have been made, people with mental health and substance use conditions continue to be denied rights as citizens, dignity as human beings, and a life free from stigma and discrimination.

Studies continue to show that people with mental health and substance use conditions are no more violent than the general population[1]. Violent acts committed by persons with mental illnesses represent a small fraction of the violence perpetrated in our country, yet these acts are frequently highly sensationalized by the media and lead to the continued stigmatization of persons with mental illnesses.

There are distinct factors other than mental illness that predispose persons to violence. In one study it was shown that people with mental illnesses who come from violent backgrounds are often violent themselves, a finding that echoes the incidence among the general population[2]. Additionally, a three year, multi-site study commissioned by the MacArthur Foundation shows that there is no difference in the rate of violence between those discharged from psychiatric treatment facilities without substance abuse problems and other people living in the same

communities who were also without symptoms of substance abuse. It appears that co-occurring mental illnesses and substance abuse significantly raises the rate of violence in both the study participant and comparison groups[3].

Law enforcement officials and legislators in states impacted by sensationalized violence have responded with reactionary proposals in the form of laws and regulations that threaten to reduce or eliminate privacy for people with mental illnesses by allowing unregulated access to medical records. States have expressed a need to have easier access to the confidential medical records of people with mental illnesses. Some suggested provisions have also stipulated that mental health professionals be required to report the names of individuals living with mental illnesses who pose a threat of violence. Both of these measures are flawed, jeopardize the liberty and care of persons with mental illnesses and should be abandoned as misguided and damaging.

Unfettered access to confidential medical records will not necessarily reduce violent incidents, but it most certainly threatens the privacy and the rights of a diverse group of individuals. Further, this idea is flawed because it stems from a common misconception that mental illness is a diagnosis, and that all mental illnesses thus have similar symptoms and expression. In fact there is great variability in the way that mental illnesses influence functioning. However, provisions compromising confidentiality draw no distinctions for symptoms, severity or persistence of illness. And confidentiality is essential to encouraging individuals to seek voluntary treatment.

The suggestion that mental health professionals be mandated to report individuals who have a potential for violence is also highly flawed and presents similar difficulties from a personal privacy and human rights perspective. Even in the case of persistent, severe, serious mental illnesses, mental health professionals possess no special knowledge, insight or ability to predict future behavior in the absence of a specific threat. Mental illness, like most human conditions, expresses itself through the complex interaction of a person's biology, psychology, social conditioning and social networks and living environments. Thus, there are no definitive predictors of violence particular to this group of individuals. The most reliable predictors of future violence, a familial history of violence, previous violent acts and substance abuse, are the same for persons with mental illness and the general population.

Perhaps most importantly, compromising consumer confidentiality erects a barrier to treatment and improved functioning. Mental illnesses are still highly stigmatized conditions, and the removal of basic confidentiality guarantees will discourage many people from seeking necessary services. The effective prevention and treatment of mental illnesses would be severely compromised by the removal of established confidentiality guarantees.

Rights in Need of Protection:

Mental Health America reaffirms its commitment to equal justice and protection of legal rights for all persons affected by mental health and substance use conditions, including children, adolescents and their families, and older adults. To carry out this principle, Mental Health America pledges itself to protecting the human and civil rights of persons who are recovering

from mental illnesses. The following rights are specifically identified because they are most likely to be abridged:

1. Rights Regarding Benefits and Service Delivery:

- The right to receive timely, culturally and linguistically appropriate and complete information about rights upon enrollment in a health plan, upon entering treatment, and at any time upon request. This information should address benefits and services, how to access available services, how to appeal a decision, how to lodge a complaint, and how to get help to navigate a service delivery system.
- The right to be fully informed of all beneficial treatment options covered and not covered, including related costs. This information should be provided in a format that meets the health literacy capacities of the consumer.
- The right to have advance directives about treatment preferences-and the right to have them honored[4] .
- The right to insurance parity, including freedom from limits based on annual and lifetime expenditures, days or visits, co-payments, or diagnosis. See Policy Number 35, Mental Health Parity in Health Insurance.
- The right to the least restrictive and least intrusive response to a need for mental health services[5].
- The right to sue the health plan for authorization denials that result in harm to the consumer.
- The right to expedited reviews and appeals from one's health plan when the situation is emergent or urgent.
- The right to access services in one's own community, including but not limited to primary and oral health care, crisis intervention, emergency services, diversion, rehabilitation, outreach, housing, employment, and mobile services, including the right to seek care from a provider who does not participate in the health plan, if the provider network is insufficient[6].
- The right to be fully involved in treatment, referral and discharge plans as they are developed, implemented and revised. Parents and guardians have the right to meaningful involvement in developing and implementing the treatment plan for their children who are still minors, as well as for their adult children if consent is given by the adult consumer.
- The right to be fully informed of treatment side effects and treatment alternatives in order to make informed decisions without coercion or the threat of discontinued services.
- The right to selectively refuse undesired treatment services without the loss of desired services[7].
- The right to receive services from providers who have appropriate linguistic skills in the needed language and/or access to appropriate interpreting support services[8].
- The right to be directed to treatment modalities that are culturally competent according to ethnicity, sexual orientation, religious beliefs, and disability [9].
- The right to access medically necessary and effective medications without being subjected to "fail first" policies, discriminatory or excessive co-payments, or time-consuming prior authorization paperwork[10].

- The right to receive appropriate, specialized and individually tailored education as a component of treatment for young people[11].
- The right to receive treatment services in one's own community, with reasonable efforts to serve children and adolescents while they remain in their homes.
- The right to be transported to treatment facilities by medical personnel, rather than law enforcement agents.

2. Rights Related to Preservation of Liberty and Personal Autonomy:

- The right to receive treatment services in a setting and under conditions that are the most supportive of personal liberty, with restrictions of that liberty only as needed to preserve safety[12].
- The right to easy access to any available rights protection service and other qualified advocates, including federally funded protection and advocacy systems.
- The right to assert grievances and to have them addressed in a timely manner, as well as with an external reviewer upon request, with no negative repercussions.
- The right to the use of voluntary admission procedures and to receive treatment on a voluntary basis wherever possible.
- The right to receive treatment and services only with informed consent, except as over-ridden by a court.
- The right to establish advanced directives and living wills and to appoint surrogate decision-makers (with a durable power of attorney), specifying how one wishes to be treated in an emergency or if s/he is incapacitated, as permitted by law[13].
- The right to be free from any form of corporal punishment.
- The right to a humane treatment environment affording appropriate privacy and personal dignity and protection from harm.
- The right to converse with others privately, to have convenient access to the telephone and mail and to see visitors during regularly scheduled hours in inpatient or residential facilities.

3. Rights Related to Competency:

- The right to be deemed competent to exercise all constitutional, statutory and common law rights and privileges and to manage one's own affairs unless restricted or limited through appropriate due process procedures [14]
- The right to inexpensive, stigma-free guardianship procedures that are the least intrusive necessary to accomplish the provision of appropriate services and which include a delineation of the duties of the guardian.
- The right to limited or partial guardianship based on proof that the particular right or privilege cannot be exercised by the individual, with the extent of guardianship tailored to the person's individual needs and based on the extent of his/her disability.
- The right to have all restrictions explicitly enumerated in the court order and to have copies provided to the interested parties.
- The right to legal counsel for every threat of loss of a privilege or right.
- The right to easy access to a person's attorney or legal representative while under a commitment order.

- Where involuntary commitment to an inpatient facility is deemed necessary, the following rights should apply (at a minimum)[15] :
    - due process hearing,
    - provision of counsel,
    - minimum burden of proof of "clear and convincing" evidence,
    - a jury trial (at the respondent's election),
    - presentation of witnesses and opportunity for cross examination,
    - clear standards for commitment based upon constitutional principles, and
    - commitment based on proof that:
        - the person requires the confinement being sought by the petitioner,
        - the place of confinement can provide the treatment being sought by the petitioner,
        - there are no less restrictive but suitable alternatives to the placement being sought, and
        - a specific overt act of dangerousness (including a stated threat).

4. Rights Related to Seclusion and Restraint

- The right to protection from the use of seclusion and restraints. Such methods should only be used after other less restrictive techniques have been tried and failed, and only in response to violent behavior that creates extreme threats to life and safety. Seclusion and restraint procedures should not be used on individuals with medical conditions that would render this dangerous[16]. See Policy Number 41, Seclusion and Restraints.
- The right to have existing advanced directives that address the use of seclusion and restraint followed by the facility. See Policy Number 49, Psychiatric Advance Directives.
- The right to review a facility's written procedures governing the use of seclusion and restraints. These procedures should require the documentation of alternative, less intrusive intervention approaches that were tried and the rationale why these failed or were not appropriate.
- The right to information that specific behaviors may result in the use of restraining procedures or seclusion. Cooperation of the consumer with the procedure should be sought.

5. Rights Related to Privacy and Information Management:

- The right to privacy and confidentiality of personal information [17].
- The right to access and supplement his/her own mental health record.
- The right of parents or guardians to access their minor children's mental health records, except where such information is protected by law.
- The right to receive information about confidentiality protocols when they join a new health plan or begin treatment with a new clinician, as well as on request on an ongoing basis.
- The right to withdraw, narrow or otherwise modify terms of consent for information to be released.
- The right to be informed of:
    - the type(s) of information that will be disclosed (nature and extent);

- who has the authority to disclose information;
- to whom the information will be disclosed; and
- for the purpose(s) the information is needed.

6. Rights Related to Specific Consumer Needs:

- **Employment**
  Mental Health America supports full implementation of the Americans with Disabilities Act and the Rehabilitation Services Act. Consumers must be given every opportunity to be gainfully employed in occupations where, with reasonable accommodation, they can contribute. Additionally, Mental Health America calls upon the mental health system to practice affirmative action in training and employing mental health consumers in professional careers in the mental health system[18].
- **Housing**
  All persons, particularly those identified as individuals with mental illnesses, are entitled to adequate, permanent housing of their choice.
- **Benefits**
  People with psychiatric disabilities need assured access to sufficient income, social supports and comprehensive health care to enjoy an adequate quality of life.
- **Consumer-Driven Mental Health Systems**
  Recovery and healing, not social control, should be the goal and outcome of the mental health system; therefore, the mental health system must be consumer-driven[19].
- **Self-Help and Peer Support Services**
  Mental Health America supports the full and sustained funding and development of user-run alternatives and additions to the traditional mental health system, self-determined and governed by and for members of the consumer community, in every community[20].
- **Ending Discrimination**
  Discrimination, abuse, ostracism, stigma and other forms of social prejudice should be identified and vigorously opposed at every opportunity.

Effective Period

This policy was approved by the Mental Health America Board of Directors on June 10, 2007. It is reviewed as required by the Mental Health America Public Policy Committee.

Expiration: December 31, 2012

1. H Stuart. A Public Health Perspective on Violent Offenses Among Persons With Mental Illness. *Psychiatric Services*. May 2001 52:654-659.
2. Heather L. Stuart, Ph.D. and Julio E. Arboleda-Flórez, M.D., Ph.D. R Gelles, Violence in the Family: A Review of the Research", *Family Violence*, Second Edition, Sage, 1987.
3. Henry J. Steadman, Edward P. Mulvey, et.al, "Violence by People Discharged From Acute Psychiatric Inpatient Facilities and by Others in the Same Neighborhoods", *Archives of General Psychiatry*, Vol. 55: 393-401, 1998.

4. See MHA Position Statement 23, Psychiatric Advance Directives
5. See MHA Position Statement 22, Involuntary Treatment
6. See MHA Position Statement 71, Access to Health Care
7. See MHA Position Statement 22, Involuntary Treatment
8. See MHA Position Statement 18, Cultural Competency
9. See MHA Position Statement 18, Cultural Competency
10. See MHA Position Statement 32, Access to Medications
11. See MHA Position Statement 41, Early Identification of Mental Health Issues in Young People
12. See MHA Position Statement 22, Involuntary Treatment
13. See MHA Position Statement 23, Psychiatric Advance Directives
14. See MHA Position Statement 22, Involuntary Treatment
15. See MHA Position Statement 22, Involuntary Treatment
16. See MHA Position Statement 24, Seclusion and Restraints
17. See MHA Position Statement 27, Standards for Management of and Access to Consumer Information
18. See MHA Position Statement 31, Employment
19. See MHA Position Statement 11, Recovery-Based System
20. See MHA Position Statement 37, Peer Support Services