Mental Health Rights

People living with mental health conditions are people. They have people they love, activities they enjoy, and dreams for their lives. As people, they deserve to be treated with dignity, and under the law they have rights and protections.

Unfortunately, it has long been the case that individuals with mental health conditions are among the most abused and discriminated against in our country. From leaving people to languish in overcrowded state hospitals to lobotomies and forced sterilization, the treatment of those with mental health conditions is a dark stain on our history as a nation.

While we have come a long way, abuse and discrimination continue to be serious problems today. The shackling or restraining of children, keeping people out of work, and denying access to services are just a few examples of the way we continue to fail the 1 in 5 Americans that has a diagnosable mental health disorder.

This is not just a small issue for a small group of people: half of all Americans will experience a diagnosable mental health condition in their lifetime. If it is not us being directly impacted, it is likely that it will be our family members, friends, or loved ones-- whether we know it or not. Beyond struggles in education or employment, we see the loss of human dignity and even human life for the people we love and care about when we do not work to address abuses in the system.

For Mental Health America, the fight against abuse and discrimination is essential to our history and continues to guide our work. MHA's symbol, which sits in our national office, is the Bell of Hope cast from the chains and shackles that were used to restrain individuals in old state hospitals. As an organization, MHA is committed to the principles of human and civil rights inherent to the concept of equal justice under the law. This includes the rights of persons with mental health and substance use conditions to:

- liberty and autonomy,
- protection from seclusion and restraint,
- community inclusion
- access to services, and
- privacy.

Liberty and Autonomy

People living with mental health conditions have the right to make decisions about their lives, including their treatment. Just as all Americans, they should be assumed competent to make their own decisions, and a refusal of any type of treatment should not be considered evidence that a person is incompetent. A person's preferences, like those referenced in a psychiatric advanced directive, should be followed and all effort should be made to engage individuals in voluntary services. In rare cases where an individual is considered an imminent danger to self or others, he or she has the right to due process, adequate representation, and appeals should there be civil commitment or involuntary treatment procedures.

MHA calls for the following policy changes:

- Advance directives have proven to be useful for maintaining and increasing the autonomy of persons with mental health conditions. MHA urges states to create and enforce laws which permit persons with mental illnesses to designate in writing, while competent, what treatment they should receive should their decisional capacity be impaired at a later date.

- There are a growing number of effective treatments for mental health conditions, including psychotropic medications. However, all medications pose some risks and many pose quite serious risks to the health of the persons who take them, particularly when medications are taken for extended periods to treat chronic illnesses. For this reason and because of its commitment to the autonomy and dignity of persons with mental health conditions, MHA strongly agrees that all persons, even persons lawfully convicted and serving a sentence of imprisonment, have a right to refuse medication and that medication may not be imposed involuntarily unless rigorous standards and procedures are met.
- Coercion occurs during many so-called "voluntary" admissions. Z*inermon v. Burch,* 494 U.S. 113 (1990). Persons facing involuntary commitment are routinely offered the option of becoming voluntary patients. However, in many treatment facilities, a person who has been voluntarily admitted is not free to leave when she or he chooses. Rather, it is common for mental health laws to permit the facility to detain a person for up to one week after she indicates a desire to leave. MHA urges states to eliminate this form of admission and admit persons to mental health facilities in the same manner as persons are admitted to medical treatment facilities for non-psychiatric illnesses.

Seclusion and Restraint

People living with mental health conditions have the right to be free from all abuses, including the practices of seclusion and restraint. Shackling, physical restraints, chemical restraints, and seclusion are among the practices used in schools and treatment facilities and throughout the criminal justice system. These practices represent failures in treatment, have no therapeutic value, and expose individuals to added trauma. Seclusion and restraint also play a role in many interactions with law enforcement, where some estimate about half of those killed by police officers has a mental illness. MHA calls for the ultimate abolition of seclusion and restraint and encourages providers, teachers, law enforcement, and consumers to work together to plan alternatives and create cultures that do not use seclusion and restraint.

MHA calls for the following policy changes:

- Psychiatric facilities should encourage people in treatment to develop psychiatric advance directives that specify conditions in which they authorize that seclusion and restraints be used and detail alternative techniques that the person in treatment requests to help reduce his or her agitation and problematic behavior prior to the imposition of seclusion and restraints. Engaging consumers in this activity should take place immediately upon admission or at the next clinically appropriate time because a disproportionately large number of seclusion and restraint events take place in the first few days after a person is admitted to a psychiatric facility.
- All staff should be trained and demonstrate competence in non-physical intervention and de-escalation techniques to prevent the use of seclusion and restraints and in the safest and least restrictive ways to use seclusion and restraints. These trainings should take place when staff are first hired and continually at regular intervals. Only staff persons who have received this training should be involved in seclusion or restraint of consumers. HHS, SAMHSA, and the Centers for Mental Health Services should develop a curriculum for states to certify trainers to do this work.
- To reduce and ultimately eliminate the use of seclusion and restraints, the federal government and the states should drastically improve the mechanisms currently available to monitor these activities and the harm caused by them to mental health consumers. As one step to improve monitoring of the use and abuse of seclusion and restraints, MHA calls on the states to publish on their websites data on the use of seclusion and restraints including the number of hours spent in restraint for each public facility and private facility contracting with the state as well as data on any injuries or deaths associated with the use of seclusion and restraint and diversion to correctional facilities.

Community Inclusion

People living with mental health conditions have the right to live and fully participate in their communities of choice. From denying someone an apartment to kicking kids out of schools, discrimination against people living with mental health conditions often occurs in areas like housing, employment, and education. Community inclusion means not only addressing discriminatory practices that exist but also providing necessary supports that allow people to live and find meaningful roles in their communities. In order to best serve the people they aim to help, services should be driven by wants and experiences of consumers to include things like peer support and self-help tools that fight isolation and promote recovery. Important laws that involve community inclusion include the Americans with Disabilities Act (ADA), Rehabilitation Act, Individuals with Disabilities in Education Act (IDEA), and important Supreme Court cases like *Olmstead vs. L.C.* To learn more about community inclusion, check out Community Inclusion After Olmstead.

MHA calls for the following policy change:

- Affiliates and advocates have long advocated for deinstitutionalization of state mental hospitals, and many have participated in DOJ audits and remedial activities, implementing *Olmstead.* The challenge now is to promote more effective community integration, including positive social interactions and support, especially of peers, access to meaningful work, and promotion of spiritual, religious, cultural and recreational opportunities. Part of providing services in the most integrated setting is providing services early and effectively so that a person avoids exclusion from the community altogether. A mix of universal and targeted early intervention and prevention services integrated into schools and communities would assure that care would truly be given in the most integrated setting possible.
- MHA is committed to protecting the gains made under the ADA in reforming state mental health systems. MHA and its affiliates should oppose legislative efforts to undermine *Olmstead* or to roll back gains made under the ADA for people with mental health conditions. MHA and its affiliates should likewise support proactive legislation in all states to advance community inclusion and integration of services, without waiting for courts to compel states to take action.
- MHA and its affiliates should ensure that community inclusion is promoted and measured as an outcome by providers, peers, and administrators of mental health care systems.

Access to Services

People living with mental health conditions have the right to receive the services they want, how and where they want them, with full explanation of insurance benefits, treatment options, and side effects. Insurance plans should provide a full explanation of services covered and implement mental health parity, which means providing coverage for mental health related services comparable to those offered for physical health services. This includes making sure people have choices in both services and providers with access to necessary and effective treatment options. Informed consent and culturally and linguistically competent services empower people to make the best decisions for their health and well-being. Important laws that involve access to services include the Affordable Care Act (ACA) and the Mental Health Parity and Addition Equity Act (MHPAEA). To learn more about rights around access to services, go to Rights of Persons with Mental Health and Substance Use Conditions**.** To learn more about services issues, check out our Services Issues page.

MHA calls for the following policy changes:

- MHA believes in full implementation of insurance parity, including freedom from limits based on annual and lifetime expenditures, days or visits, co-payments, or diagnoses. Advocates should work with states attorneys general to set up complaint lines and publicize them widely to ensure parity is being implemented.

- Individuals have the right to be fully informed of all beneficial treatment options covered and not covered, including related costs, in clear language. Advocates should work to ensure that insurance companies provide comprehensive, accurate information about benefits and services, how to access available services, how to appeal a decision, how to lodge a complaint, and how to get help navigating a service delivery system.
- MHA supports the right to access medically necessary and effective medication without being subjected to "fail first" policies, discriminatory or excessive co-payments, or time-consuming prior authorization and paperwork processes. In addition to expedited reviews and appeals from one's health plan when the situation is emergent or urgent, individuals have the right to sue the health plan for authorization denials that result in harm to the consumer. Advocates should help individuals appeal denials and work to change discriminatory policies that keep people from accessing the services they want and need.

Privacy

People living with mental health conditions have the right to privacy and to manage who can see their healthcare information. This includes controlling who sees their health information and the ability to access and supplement their mental health records. Health plans and providers should provide information about privacy and confidentiality protocols. For example, many mental health professionals are required to report child abuse; therefore, an individual should know prior to engaging in treatment that any disclosure of child abuse may potentially result in a report to respective authorities. Information about privacy and information sharing should be given when a person joins a health plan or begins treatment with a new clinician and should be available on an ongoing basis, with the ability to withdraw, narrow, or otherwise modify terms of consent for what is to be shared. Important laws related to privacy include the Health Insurance Portability and Accountability Act (HIPAA) and state duty-to-warn laws. To learn more about privacy, check out Standards for Management of and Access to Consumer Information.

MHA calls for the following policy changes:

- For court orders authorizing disclosure of confidential information for other than criminal purposes, HIPAA requires that the consumer receive formal notice of the request and an opportunity to respond but does not set a standard, which is left to state law. MHA advocates that the judge weigh the need for disclosure against the potential harm to the consumer and to the clinician-consumer relationship and its impact on the treatment process. HIPAA requires that the order limit disclosure to information essential to the demonstrated purpose and provide protection against future public scrutiny, such as by sealing court records.
- MHA generally opposes special protections of certain health related information because there is no evidence that additional formalities increase privacy, and such special protections compromise integration of care. Examples of "super-confidential" information include: genetic information and information pertaining to school records, substance abuse, mental health conditions, HIV testing, and sexually transmitted diseases, as defined and protected by specific federal and state laws and regulations. MHA does support the HIPAA exemption for psychotherapy notes, as defined in 42 CFR 164.501.
- Individuals should have the right to release HIPAA-protected information to their designated healthcare proxies and in their psychiatric advance directives, and should routinely do so. State law presumptions could help consumers to avoid HIPAA impediments to sharing information as they wish.

https://www.mhanational.org/issues/mental-health-rights