PUBLIC POLICY PLATFORM

of

NAMI

The National Alliance on Mental Illness

Tenth Edition
November 2013

NAMI
National Alliance on Mental Illness

NAMI advocates for research and services in response to major illnesses that affect the brain, including schizophrenia, schizoaffective disorder, bipolar disorder, major depressive disorder, obsessive-compulsive disorder, panic and other severe anxiety disorders, borderline personality disorder, post traumatic stress disorder (PTSD), autism and pervasive developmental disorders, and attention deficit/hyperactivity disorder.

NAMI establishes this policy statement to advance its mission through advocacy and education. This is an evolving document.

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The Purpose of the Public Policy Platform

NAMI advocates for all people with mental illness and their families. NAMI strategically focuses on the most "serious mental illnesses" where the need is greatest**.** NAMI's policy is to acknowledge that mental illnesses are illnesses that affect the brain. Therefore, throughout this document, we are discussing the term "brain disorder(s)" interchangeably with mental illness and serious mental illness**.**

NAMI advocates for research and services for major illnesses that affect the brain. NAMI requires that all NAMI documents and NAMI co-authored documents use language that puts people first. For example, "people or persons with serious mental illnesses" instead of "mentally ill people" or "the mentally ill"; and "offenders with serious mental illnesses" instead of "the criminally insane."

Stigma and Discrimination

NAMI condemns all acts of stigma and discrimination directed against persons with mental illnesses, whether by intent, ignorance, or insensitivity. Epithets, nicknames, jokes, advertisements, and slurs that refer to persons with serious mental illnesses in a stigmatizing way are cruel. NAMI considers acts of stigma to be discrimination.

NAMI believes, in accordance with current scientific evidence, that persons who are receiving appropriate treatment and services for a mental illness are no more violent than the population at large. NAMI deplores the portrayal in literature, films, and television of persons with serious mental illnesses as being prone to violence. These frequent depictions are hurtful stereotypes. The truth is that persons with serious mental illnesses are more often the victims of violence.

NAMI further believes that mental illness is essentially biological in nature. Mental illness affects behavior and behavior can affect mental illness - but mental illnesses are not behavioral. The term "behavioral health" obscures and hinders effective treatment of co-occurring disorders. Also, because behavior is perceived as a matter of choice ("good" or "bad" behavior), the very term "behavioral health" can add to the stigma and discrimination endured by people living with a mental illness.

NAMI especially deplores the exploitation of people with mental illnesses by journalists, advertisers, advertising agencies, the entertainment industry, and others for commercial gain or other advantage.

Stigma and resulting discrimination can be an especially prevalent challenge in the military services, the National Guard and Reserves. Some mental illnesses do occur in the context of

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traumatic exposures to war. Mental illnesses must not be allowed to stigmatize and limit opportunities for continued military service and advancement.

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1. Identity and Mission

1.1 NAMI is a grassroots organization of individuals with mental illnesses, especially serious mental illnesses, their family members, and friends whose mission is to advocate for effective prevention, diagnosis, treatment, support, research and recovery that improves the quality of life of persons of all ages who are affected by mental illnesses.

1.2 The primary functions of NAMI are support, education, and advocacy for:

- consumers and their families;
- research and services; and
- the education of all professionals, providers, and the general public. An individual with a serious mental illness is sometimes referred to as a consumer. When speaking of NAMI members in general, we speak of family and that includes the consumer as a family member. We speak of consumer when it is necessary to make the distinction.

1.3 NAMI promotes the prevailing scientific judgment that "severe mental illnesses" are brain disorders, which, at the present time, are neither preventable nor curable, but are treatable, manageable and recoverable with combinations of medication, supportive counseling, and community support services, including appropriate education and vocational training. The causes of serious mental illnesses are complex, and they are not understood thoroughly. There is a genetic component to some serious mental illnesses. Although stress or drug and alcohol abuse can precipitate or aggravate episodes of an illness, they are not primary causes.

1.4 NAMI's roots grew from the needs of people for knowledge, understanding, sharing of grief, relief from guilt and stigma, mutual support, and mutual love. Increases in NAMI's membership are likely to be concentrated in families, consumers and others who have these same concerns. Family means consumers and their parents, siblings, adult children, spouses, civil partners and domestic partners, and other involved relatives.

1.5 While primary peer support is concentrated in local affiliates, all components of NAMI declare:

(1.5.1) Together we can give each other strong support;
(1.5.2) The illness is treatable;
(1.5.3) It's not anyone's fault;
(1.5.4) You don't need to explain anything–we already know;
(1.5.5) You can survive as an intact family; and

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(1.5.6) With dedication and unity, we have enormous strength through which we can accomplish constructive change.

1.6 Persons with mental illnesses share many similar problems with persons with other disorders and disabilities. To achieve our own goals, NAMI supports to the fullest extent possible solidarity with those persons with disorders and disabilities to effect positive changes in societal attitudes, government, education, and public and private institutional responsiveness. NAMI will advocate for the rights of persons with serious mental illnesses, even when our views conflict with the views of other disability groups. NAMI places the highest priority on medical treatment, services, education, rehabilitation and recovery for persons with serious mental illnesses, as well as research aimed toward the ultimate prevention and cure of these disorders.

2. Priority and Special Population

2.1 Priority Population

NAMI advocates for the most effective and appropriate care and treatment and provision of services for people who experience a mental illness. NAMI's priority populations are children, youth and adults with serious mental illnesses who need services and support, often throughout their lives. These include children and adults who have diagnoses that are considered major mental illnesses that significantly impair major life activities, interpersonally, vocationally, educationally, and in managing activities of daily living.

Diagnosis of serious mental illness includes schizophrenia, schizoaffective disorder, bipolar disorder, major depressive disorder, obsessive-compulsive disorder, panic and other severe anxiety disorders, borderline personality disorder, post traumatic stress disorder (PTSD), autism and pervasive developmental disorders, and attention deficit/hyperactivity disorder as well as co-occurring substance use disorders. These disorders represent those diagnoses that current scientific data and consensus conclude are identifiable, disabling medical illnesses, with significant biological underpinnings, and require treatment.

(2.1.1) Other mental illnesses that result in:

(2.1.1.1) seriously disabling consequences; or
(2.1.1.2) a high risk of co-morbidity or mortality: and
(2.1.2.1) have a long term course.

2.2 Additional Support

NAMI believes that individuals with serious mental illnesses often require additional support to have their specific needs met and to ensure their access to integrated systems of care, education, and rehabilitation.

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2.3 Cultural Diversity

(2.3.1) Persons of different ages, and of varying cultures, racial, religious, ethnic, sexual orientation, gender, gender identity, disability, including person who are deaf and hearing impaired, and those for whom English is not the primary language have unique characteristics that sometimes cause them to be partially or poorly served or excluded from existing treatment, training, and rehabilitation programs, which are not relevant to their needs. These differences must be respected, embraced, and accorded appropriate representation in mental health care policy, administration, diagnosis, treatment, services, and support in provider and governmental organizations, as well as throughout the organization and operation of NAMI.

(2.3.2) NAMI supports expanded efforts toward recruitment and training of professionals from these groups, the development and distribution of culturally and linguistically appropriate materials for use in education, encouragement of their participation in programs and services, and outreach efforts targeted to these underserved and excluded groups.

(2.3.3) NAMI urges the incorporation of ethnic and cultural perspectives and competence into the design and implementation of programs and procedures for persons with mental illnesses so that diagnostic evaluations, consumer and family communications, and the provision of treatment and services will be free from bias and cultural impediments.

(2.3.4) NAMI believes that providers must have training and sensitivity to cultural diversity.

(2.3.5) NAMI deplores the higher rates among minorities of involuntary commitment and incarceration in penal facilities that occurs among minorities with serious mental illnesses versus non-minorities with similar diagnoses.

2.4 Older Adults with Mental Illness

(2.4.1) NAMI recognizes that the proportion of older adults with mental illnesses will increase as the proportion of older adults in the overall population disproportionately increases. Older age presents added challenges for persons with mental illnesses, especially serious mental illnesses. Treatment must be monitored and adjusted with respect to the metabolic changes coming with aging. Treatment and support need to take into

consideration limiting physical, social, economic and other conditions associated with aging. Certain circumstances of aging, such as loss of family, social isolation and infirmity can be triggers for the onset of mental illnesses, including alcoholism and serious depression, among older people. Older persons with mental illnesses also face the loss of family and other caregivers as well as the insufficiency of geriatric health practitioners, including mental health practitioners.

(2.4.2) NAMI calls for Medicare, Medicaid and all public and private health care coverage to provide a suitable, non-discriminatory continuum of community-based treatment, housing and support for older adults with mental illnesses integrated with overall wellness. This should always be based on the least restrictive alternative and should only include nursing homes, and skilled nursing facilities if based on medical conditions other than mental illness. NAMI opposes the practice of indiscriminately administering psychotropic medications to older adults for purposes of sedation or behavioral compliance.

(2.4.3) NAMI supports expanded research on mental illness and aging as well as expanded recruitment, education and training for health and mental health care providers, family members and other caregivers with respect to the specialized needs of older adults with mental illnesses.

(2.4.4) NAMI calls for more effective collaboration between advocates for persons with mental illnesses and advocates for older adults at the national, state and local level.

2.5 Adults Who Are Veterans and Active Duty Military

(2.5.1) NAMI believes that persons with mental illnesses who are veterans, on active military duty, in the National Guard, or in the Reserves, as well as their families, should receive the same full range of integrated diagnosis, treatment services, and supports across a continuum of care as should be available to all people with serious mental illnesses.

(2.5.2) Individuals who are veterans, on active military duty, in the National Guard, or in the Reserves, as well as their family members must receive the same level of care and treatment regardless of the provider.

(2.5.3) NAMI calls for effective diagnosis, treatment and referral for active military duty personnel with serious mental illnesses, upon induction and throughout the period of military service.

(2.5.4) NAMI recognizes the need to make effective, integrated treatment programs for co-occurring disorders, including medications, available to veterans and active duty military personnel.

(2.5.5) NAMI recognizes that women, who are a more substantial proportion of veterans and active duty military personnel than ever before, may present mental health care needs differently and require treatment appropriate to their special needs.

(2.5.6) NAMI urges action by the Department of Defense, by executive order of the President of the United States or by act of the United States Congress to authorize that the Purple Heart Award for military service resulting in combat related, medically documented related serious mental illnesses, including post-traumatic stress and mental illnesses induced by traumatic brain injury.

(2.5.7) NAMI recognizes that returning veterans, National Guard members and reservists with mental illnesses face discrimination as well as higher rates of unemployment and underemployment than in the general population. Effective treatment and support for these veterans must include access to effective education, training, referral services, hiring preferences, supported employment, professional credentialing and other resources needed to return to work. NAMI also supports recognition of military training credits in qualifying for civilian employment.

2.6 Persons Who Are Homeless and/or Missing

NAMI believes appropriate treatment for persons with serious mental illness leading to recovery, resiliency and wellness cannot be realized without appropriate housing. Persons with serious mental illnesses have the right to safe, decent and affordable housing that meets their needs.

(2.6.1) NAMI advocates for the right to treatment for persons with serious mental illnesses who are homeless and for those at risk of becoming homeless. These citizens have the same needs and rights to shelter and treatment as all other persons with serious mental illnesses. NAMI believes that persons with serious mental illnesses who are homeless should have individualized treatment plans that are integrated into existing systems of care and related health and human service systems.

(2.6.2) NAMI urges that service providers, professionals, and others assisting persons with serious mental illnesses who are homeless show them and their families common courtesy, compassion, and respect.

(2.6.3) When helping to reunite families, NAMI appeals to service providers, professionals, and others assisting persons with serious mental illnesses who are homeless to do what is in the best interest of all concerned, consistent with ethical and medical practices and applicable legal guidelines.

(2.6.4) NAMI deplores the commonplace use of jails and prisons to warehouse persons with serious mental illnesses who are homeless.

(2.6.5) NAMI believes that an adult who once served his or her country in uniformed military service should never become homeless. NAMI urges federal, state and municipal governments to make special efforts to address homelessness in the veterans population through better dissemination of information and coordination of programs that provide treatment, support, assistance and housing options.

2.7 Persons Infected with the HIV Virus

(2.7.1) NAMI believes that all persons with serious mental illnesses should be encouraged to be tested for HIV. NAMI believes that persons who test positive should receive appropriate treatment for both their serious mental illnesses and HIV-related illnesses in the least restrictive setting that is safe for all concerned. The results of testing should be shared only on a "need to know" basis and should include families if they are primary caregivers. If families are not primary caregivers, persons with serious mental illnesses should be encouraged to share this information on a voluntary basis.

(2.7.2) Persons with serious mental illnesses living in institutional settings have been identified as high risks for HIV infection. Therefore, NAMI believes that all persons with serious mental illnesses in institutional settings should be offered HIV testing and strongly encouraged to participate in testing.

(2.7.3) NAMI urges that education, counseling, and peer support should be made available to the person with a serious mental illness who tests HIV positive and, whenever possible, should be offered to their family and staff as well.

2.8 Children with Serious mental illnesses

(2.8.1) NAMI believes that children and adolescents with serious mental illnesses have the right and must be offered the opportunity to thrive in nurturing environments.

(2.8.2) NAMI believes that, at the earliest possible time in their lives, all children and adolescents with serious mental illnesses deserve to be diagnosed, appropriately treated, and offered the services necessary to achieve and maintain their recovery.

(2.8.3) NAMI believes that children and adolescents with serious mental illnesses should be treated in their homes and in their communities whenever that level of treatment is appropriate to their clinical need and they should be offered a full array of demonstratively effective services at that time.

(2.8.4) NAMI urges parents and caregivers to become well informed about the array of treatments and services that are or should be available in their community. They should be aware of the special education services that are available for the child who may require those services because of a developmental disability (DD) and/or serious mental illness.

(2.8.5) NAMI calls on all school administrators, teachers, and other education professionals to follow the requirements of the Individuals with Disabilities Education Act (IDEA) in order to ensure that students with serious mental illnesses receive an appropriate education and related services as mandated by the law and to ensure that these students have the opportunity to lead independent and productive adult lives.

(2.8.6) NAMI calls on federal, state and local education officials to immediately address the low academic achievement and unacceptably high drop-out and failure rates of students in the "emotional disturbance" category of the Individuals with Disabilities Education Act (IDEA). Students living with serious mental illnesses are included in that category.

(2.8.7) NAMI calls for strong interagency collaboration between all child- and family-serving agencies, including state and local mental health systems; public and private schools; child welfare systems; and juvenile justice systems.

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(2.8.8) When children and adolescents are detained for mental health care or juvenile justice custody due to behavior that might be caused by a serious mental illness, their clinical status must first be evaluated by a qualified mental health professional and must be taken into account before establishing the appropriate conditions for treatment or detention. When detained, children and adolescents with serious mental illnesses must never occupy the same waiting area, living quarters, evaluation and

treatment spaces as adults being served in that setting. Girls who are detained should always be supervised by a female attendant.

(2.8.9) When children and adolescents appear to be experiencing a crisis associated with a serious mental illness, qualified mental health professionals should always be among the first responders contacted. Families should not be directed to law enforcement when a child is experiencing a psychiatric crisis at home or in the community. Every community must have access to an effective and appropriate crisis response system for children and adolescents with serious mental illnesses.

(2.8.10) Schools should not call law enforcement as the first responder in a psychiatric crisis. The intervention of law enforcement personnel either in schools or the community should always be a last resort and should only occur when it is the only option to protect the child and/or the public. School personnel should be trained to effectively de-escalate a psychiatric crisis and schools should have appropriate links to crisis services in the community mental health system.

(2.8.11) In the event that a child exhibits or threatens aggression or self-injurious behavior during a crisis and transportation to a treatment facility is necessary, a qualified mental health professional and/or appropriately trained law enforcement officer must first de-escalate the crisis and then arrange for transportation, preferably in a family vehicle if appropriate or in the least threatening and stigmatizing vehicle available. Adult family members, caregivers, persons known to and trusted by the child, or qualified mental health service providers should accompany the child in transit. When being transported for psychiatric evaluation, psychiatric care or juvenile detention related to a mental health issue, children and adolescents should never occupy the same vehicle or detention areas as adults. Girls who are being transported should always be supervised by female attendants. Using the appropriate vehicle and ensuring appropriate conditions for transportation, during psychiatric crisis, can avoid re-traumatizing the child, the adolescent and the family.

(2.8.12) NAMI believes that families should never be coerced to relinquish custody of their dependent children with serious mental illnesses in order to obtain care, treatment, on an education. The health care service system must be restructured to ensure that children and families are never forced to seek mental health services in the child welfare and juvenile justice systems.

(2.8.13) NAMI recognizes the critical role that families play in the recovery and development of their children. Therefore NAMI supports the right of

families of children who have serious mental illnesses to visit and otherwise maintain as normal contact as appropriate with their children when they are being served in hospitals and other residential facilities. These facilities must not impose overly restrictive visitation limits that prohibit families from visiting their child.

(2.8.14) NAMI calls on national, state and local leaders to take immediate action to end the workforce shortage in children's mental health services.

(2.8.15) NAMI believes that all primary care providers, including pediatricians, family practice physicians, and advanced practice nurses must be trained to recognize the early warning signs of serious mental illnesses in children, to provide effective treatment as necessary and to develop collaborative agreements with child psychiatrists to whom they can refer children and families for specialized services.

2.9 Minor Children of Parents with Serious mental illnesses

NAMI recommends that NIMH study the special problems of minor children whose parents have serious mental illnesses. The diagnosis of a serious mental illness alone is not sufficient grounds for losing custody of one's children.

3. Treatment

3.1. Access to Treatment

(3.1.1) NAMI believes that individuals with mental illnesses must have access to treatments that have been recognized as effective by the Food and Drug Administration (FDA) and the National Institute of Mental Health (NIMH).

NAMI is adamant that individuals with mental illness have access to clinically appropriate medications, evidence based services and treatment, including psychotherapy, that are provided in a person centered approach.

(3.1.2.1) NAMI strongly opposes measures that are intended to limit, or actually do limit, the availability and right of individuals with mental illnesses to receive treatment with the most individually appropriate**,** effective**,** and clinically indicated medications.

(3.1.2.2) No one currently taking a medication and doing well on that medication should be switched to another medication, even the

generic version of the original, simply because the second medication is cheaper.

(3.1.2.3) Psychotherapy should be a part of the treatment regime for individuals with mental illness when the treatment team, including the consumer, determines that this is an appropriate option.

(3.1.2.4) The individual with mental illness should have the right to engage their preferred provider or change providers as meets their needs.

3.2 Early Diagnosis

(3.2.1) Early diagnosis and early initiation of treatment are both medically and clinically effective and cost effective. However, safeguards must be established to ensure against the abuse of over-diagnosis and over-prescribing of medications, particularly with children, adolescents, people of color and persons who are elderly.

(3.2.2) NAMI urges states to follow the broad mandate included in the federal Medicaid law that requires states to provide early and periodic screening, diagnosis and treatment (EPSDT) for Medicaid eligible children and adolescents. Under EPSDT, Medicaid eligible children are entitled to health care screenings, including mental health screens, and access to all medically necessary mental health services necessary to improve the child's condition. Treatment plans for children and adolescents should be reviewed, at a minimum every three months, however more often when clinically indicated to ensure the safety of children and youth and when medications are prescribed and/or dosages are modified.

3.3 Mental Health Screening

(3.3.1) NAMI strongly supports Goal 4 of President Bush's New Freedom Commission report on mental health issued in July 2003 and calling for early mental health screening. In this nation, approximately 10% of children and adolescents have mental illnesses, yet only 20% of them are identified and receiving services. Mental health screening is essential to address this gross under-identification of youth with mental illnesses. Research shows that early identification and intervention leads to better outcomes and may lessen long-term disability. It also avoids years of unnecessary suffering.

(3.3.2) Screening for the health and well being of children is a well-established practice in this country. We screen for vision, lead poisoning, hearing, scoliosis, tuberculosis, appropriate developmental progress and more. Campaigns of misinformation, stigma and fear must not stand in the way of appropriately identifying youth with mental illnesses and intervening with appropriate services.

(3.3.3) Federal, state and local leaders should take affirmative steps to implement mental health screening for children and adolescents, **with the following guidelines and protections in place**:

(3.3.3.1) Mental health screening must be voluntary and available for all children.

(3.3.3.2) Parental consent or consent from legally authorized surrogates must be obtained for all mental health screening.

(3.3.3.3) Mental health screening must not be used in a discriminatory manner.

(3.3.3.4) All individuals administering mental health screening must be appropriately trained and qualified both to administer the screening instruments and to interpret the results.

(3.3.3.5) All information related to screening must be kept strictly confidential and the privacy of youth and their families must be protected.

(3.3.3.6) All mental health screening instruments must be shown to be reliable and effective in identifying children in need of further assessment.

(3.3.3.7) Validity studies must be done to ensure that screening instruments are culturally and linguistically appropriate and administered in a manner appropriate for culturally and racially diverse communities.

(3.3.3.8) Schools must never use mental health screening results or the refusal to consent to screening as a basis for any adverse action against a child or family.

(3.3.3.9) All children identified through screening as potentially requiring mental health services must be referred for an immediate

comprehensive mental health evaluation by a qualified and trained professional.

(3.3.3.10) Children ultimately identified as requiring mental health services must be immediately linked to and offered appropriate treatment and services and provided with comprehensive information about treatment options, the mental health treatment system, and family and community support resources.

(3.3.3.11) Early identification and intervention must be part of a national effort to build a comprehensive children's mental health system of care for the millions of children and adolescents who require these services and their families. Families with children living with mental illnesses deserve nothing less.

3.4. Individual Treatment Plan

(3.4.1) Every person with a serious mental illness must have an individual treatment plan (ITP) responsive to his or her changing needs. The plan needs to include, but not be limited to, health care, education, housing, rehabilitation services, and community support services. Treatment for persons with serious mental illnesses, who have other disorders or disabilities, including co-occurring mental illness and substance use disorders, should encompass a wide array of options. Options should be determined by the consumer in conjunction with family members and those significantly involved in treatment and service provision.

(3.4.2) A treatment plan reflecting assessed needs may include a range of available services. Criteria for determining the treatment plan should include assessment of behaviors resulting from changes in life circumstances as well as the skills development and social supports needed to respond to these changes.

3.5 Outpatient Treatment

(3.5.1) Outpatient treatment must be readily accessible to the individual in his or her own community. The treatment options must include appropriate medications including new-generation medications, symptom therapy, psychotherapy, assertive community treatment (ACT), rehabilitation and peer support. Evidence based practices such as dialectical behavior therapy and cognitive behavioral therapy should be available as options for treatment.

(3.5.2) Easily accessible emergency services must be readily available 24 hours a day, seven days a week, and should be accessible to crisis intervention teams of local police departments. If a person has a serious mental illness and is subject to arrest, specially trained personnel must have authority to determine the intervention needed and to refer to the appropriate level of care. All emergency services, including those in inpatient hospitals, must be staffed by trained mental health professionals.

(3.5.3) Partial hospitalization, also known as day treatment programs, should be used selectively with monitoring to ensure that the stay is goal-oriented.

(3.5.4) Community systems must be comprehensive, person-centered, and integrated. These systems should include medical, dental, daily-living skills, peer support, supported housing, education, pre-vocational and vocational training and a broad array of services that support wellness, resiliency and recovery.

3.6 Inpatient Treatment

(3.6.1) Inpatient treatment means treatment in any licensed hospital with 24 hour staffed psychiatric beds. An inpatient facility must be equipped to serve people at risk of harm to self or others or who are gravely disabled and in need of a safe, secure setting that is patient and family centered, recovery oriented, culturally sensitive, prepared to provide comprehensive treatment as well as rehabilitation, recovery opportunities and provides a discharge planning process that connects individuals to appropriate community services, supports and housing.

NAMI believes that every psychiatric inpatient facility must be held to the same standards of excellence demanded of every medical general and tertiary care hospital. People with mental illness who require inpatient care have a right to expect and receive timely state of the art medical and psychiatric treatment, delivered by an adequate number of competent hospital staff in a safe and secure environment.

(3.6.2) Acute inpatient treatment is necessary when a person with a primary psychiatric diagnosis or co-occurring disorder is in need of urgent care because of a rapid escalation of symptoms and is likely to respond to treatment in a relatively short period of time and to be ready for reintegration into the community with appropriate community treatment, supports and housing.

(3.6.3) Longer term inpatient treatment is required when a person with a primary psychiatric diagnosis or co-occurring disorder has symptoms that are intractable or their functioning is impaired such that the person requires a longer duration of treatment. Treatment must provide further stabilization, engage the person in comprehensive treatment and incorporate rehabilitation and recovery activities. A hospital and community discharge planning team must work with the person, their family and community providers to transition the person to the least restrictive level of care that promotes resiliency and recovery.

(3.6.4) NAMI believes that both acute and longer term inpatient treatment are vital components in the array of treatment interventions and services that are necessary to assure a timely and durable recovery from the symptoms of mental illness. Recognizing that psychiatric inpatient treatment may be involuntary or otherwise restrictive of a person's freedom, it must only be initiated after a competent and comprehensive clinical evaluation by an appropriately licensed mental health professional that demonstrates the clinical need for inpatient care. It must be directed by an individualized treatment plan (ITP) and result in discharge to appropriate treatment and services as soon as inpatient treatment goals are met. No one should be retained in inpatient treatment when such treatment is no longer clinically indicated. It is the responsibility of the inpatient facility to work with the person, their family and community providers to develop appropriate community treatment, supports and housing that will be in place upon discharge. Discharge from inpatient treatment should never be determined by a facility's need to address its census issues.

3.7 Family Involvement in Treatment

(3.7.1) Family members are a central resource in the treatment of children and adults living with serious mental illnesses and should be an integral part of the treatment team and empowered to facilitate mutually agreed upon treatment team goals. Research overwhelmingly shows that when families take an active part in treatment decisions, consumer outcomes are better. While families do not cause serious mental illnesses, families bring a knowledge of and relationship with the consumer that is unique and can be a significant help in determining the best course of treatment and recovery.

(3.7.2) In no case should the presence of a loving, caring family be used as a substitute for a delivery system that provides for all of the person's treatment and rehabilitative needs leading to recovery, resiliency and wellness.

(3.7.3) The consumer is the reason the mental health treatment system exists. The consumer–or in the case of an unemancipated child, the child's representative–is the most important member of the treatment team.

The consumer should be encouraged to participate fully in planning, monitoring, and evaluating treatment. Other treatment team members should assure that their focus is on meeting the consumer's needs, not the desires of the system or service providers.

(3.7.4) Consumers and family members must be treated with compassion, dignity and respect. They must also be provided with extensive education to understand all aspects of the illness in order to be more effective in treatment leading to the consumer's recovery, resiliency and wellness.

(3.7.5) Family and consumer advocacy should always be encouraged. In circumstances where the mental health system is understaffed, under-financed, and services uncoordinated, or other problems impede proper service delivery, family and consumer advocacy is effective and powerful.

(3.7.6) Sometimes, because of stigma and lack of information regarding serious mental illnesses, the family is not involved. Their absence does not usually indicate that they have no concern for their loved one's well being. Mental health workers must understand this and work to strengthen family relationships. When family members become educated and are respectfully involved, in a way they experience as empowering, their approach to the individual with mental illness and the treatment system changes.

(3.7.7) In such cases where consumers do not want their family members involved, their wishes must be respected. At the same time, extensive educational efforts should be made to help these consumers understand that their families are not to blame for the illness and that recovery is more likely if all interested parties work together.

(3.7.8) All treatment and services provided to children living with serious mental illnesses living with their families should be child centered and family driven, with the needs of the child and family dictating the types and mix of services provided. The families, surrogate families and legal guardians of children with serious mental illnesses should drive the treatment planning and delivery process, in close consultation with the treating providers. Children living with serious mental illnesses should be included in all aspects of treatment planning whenever possible.

Family driven means that the treatment provider gives the family the information and skills to make informed decisions as equal partners in the treatment planning and delivery processes.

Families must have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory, and nation. This includes:

- choosing supports, services, and providers;
- setting goals;
- designing and implementing programs;
- monitoring outcomes;
- partnering in funding decisions; and
- determining the effectiveness of all efforts to promote the mental health and well being of children and youth.

(3.7.9) Child-serving systems and their funding mechanisms should be designed to allow families with children living with serious mental illnesses to easily access appropriate mental health and related services. Child-serving systems should be designed with cross-system and interagency collaboration to ensure an appropriate coordination of services for children and families. Families should not be required to navigate multiple, complex and overly bureaucratic systems to access appropriate services for their child.

3.8 Outcome Measures

NAMI believes that community-based services must include regular measurements of consumer and family satisfaction and dissatisfaction with these services. These measurements are best conducted by independent consumer and family satisfaction teams who interview service recipients using continuous quality improvement methodology.

3.9 Non-endorsement of Specific Medications or Treatment Modalities

As a matter of policy, NAMI does not endorse any specific treatment or service for mental illnesses. NAMI does advocate evidence based programs and practices, best practices, promising practices and clinical practices when they apply to the population being treated.

3.10 Access to Psychiatric Medications

(3.10.1) NAMI supports the following integrated and comprehensive federal strategies to ensure open access to psychiatric medications.

(3.10.1.1.) Increase the Federal Medical Assistance percentage (FMAP);

(3.10.1.2) The Medicare prescription drug benefits must provide full access to psychiatric medications;

(3.10.1.3) Advocate with the Center for Medicaid and Medicare Services (CMS) to provide written guidance on carve outs to Medicaid directors;

(3.10.1.4) Support increased funding to NIMH for research on psychiatric medications and access to these medications.

(3.10.2) NAMI supports the following integrated and comprehensive state strategies to ensure open access to psychiatric medications:

- Oppose, at all costs, "fail first" provisions in state laws and policies;
- Support efforts by pharmaceutical companies to develop new medications but oppose pricing practices that make these medications unaffordable;
- Support adjunctive education programs about psychiatric medications and safe prescribing practices;
- Support the development of explicit medication access protocols.

3.11 Prescription Privileges for Psychologists, Workforce Shortages

NAMI does not endorse proposals currently before state legislatures to expand prescribing privileges to psychologists. NAMI acknowledges that serious shortages exist in the mental health professional workforce, particularly in public mental health systems and in rural and medically under-served regions of the country. However, there is no current evidence that expanding prescribing privileges to psychologists will address these shortages.

Additionally, NAMI calls upon the Substance Abuse and Mental Health Services Administration (SAMHSA), working in coordination with the National Institute of Mental Health (NIMH) and other relevant federal agencies, to undertake a national study and issue a report evaluating the scope and extent of workforce shortages in the mental health field, describing the impact of these shortages on access to quality care and treatment for people with serious mental illness, and recommending strategies for attracting and retaining qualified professionals in the

mental health field, including in rural or medically under-served regions of the country.

3.12 Cultural Competence

(3.12.1) Cultural competence is a goal toward which all professionals, agencies and systems must strive. Becoming culturally competent is a developmental process that incorporates—at all levels—the importance of culture, an assessment of cross-cultural relations, vigilance about the dynamics that result from cultural differences, the expansion of cultural knowledge and the adaptation of services to meet cultural needs. It is also a developmental process that can improve the quality of care and mental health service delivery system for all Americans.

(3.12.2) Culture is broadly defined as a common heritage or set of beliefs, norms, and values. It refers to the shared, and largely learned attributes, of a group of people, and has been found to play a pivotal role in mental health, mental illness and mental health services. Persons of different cultures such as varied ages, religions, racial and ethnic groups, gender, sexual orientation, gender identity, disability, including persons who are deaf and hearing-impaired, and those for whom English is not their primary language, have unique characteristics that have been found to cause them to be partially or poorly served or excluded from existing mental health treatment, trainings, and rehabilitation programs, and to receive services that do not reflect their cultural needs and preferences . Treatment plans must be relevant to the consumer's culture, needs and life experiences. Plans shall be developed by providers who have the knowledge, skills and attitudes necessary to provide effective care for diverse populations.

(3.12.3) Mental health providers must be aware of and have an understanding of the wide-ranging role culture plays in shaping what people bring to the clinical setting and how it shapes treatment professionals. They must also consider cultural factors and influences when working with people of all ethnicities and cultures, as these areas account for variations in the way consumers communicate their symptoms, which ones they choose to report, whether they seek treatment or not, what type of help they may seek, and what types of social support and coping styles are available. Cultural influences have also been found to shape treatment professionals, who share a set of beliefs, norms and values with their colleagues. As a result, clinicians can view symptoms, diagnoses and treatments in ways that diverge from the views of the patients they treat. Considering, and more importantly, demonstrating commitment to

understanding and respecting cultural factors and influences are key components of providing culturally competent mental health care.

(3.12.4) Availability of, access to, and the provision of high-quality and meaningful mental health services received by diverse communities are positively affected by an increased level of cultural competence within the mental health care system. Thus, to effectively serve diverse populations, mental health systems need to fully embrace and prioritize cultural competence. Additionally, at a minimum mental health systems must ensure that mental health provider organizations conduct annual cultural competence self-assessments, develop culturally and linguistically competent plans to address areas that would enhance the delivery of culturally and linguistically competent service delivery, incorporate such plans into the organization's quality improvement programs and strategic plans, establish cultural competence committees or work groups, and support the ongoing development of cultural competence skills among all of its employees and volunteers. Plans should identify key performance indicators that will be closely monitored and enforced.

(3.12.5) Individuals with Limited English Proficiency (LEP) and persons who are deaf and hearing impaired must have equal access to mental health treatment - Culturally competent communication must be available at all times through bilingual providers, certified interpreters, interpreter phone lines, and materials and forms in languages other than English. Mental health provider organizations must provide these services at all points of contact and in a timely manner during all hours of operation. It is not acceptable to use uncertified employees, family members, or friends as substitutes for qualified interpreters.

(3.12.6) Individual and organizational mental health providers and administrators must comply with Section 601 of Title VI of the Civil Rights Act of 1964, which states that no person shall ``on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. Disparities in the availability of, access to and the provision of quality mental health services experienced by individuals from varied cultures is discrimination and cannot be tolerated any longer. Providers and administrators must also be made to comply with Executive Order 13166, which aims to improve access to federally conducted and federally assisted programs and activities for

persons who, as a result of national origin, are limited in their English proficiency.

(3.12.7) The federal government, in order to effectively monitor and enforce Title VI of the Civil Rights Act, should mandate compliance agreements that require recipients who operate mental health programs to ensure that they have language access services available to meet the needs of limited English proficient individuals seeking services at all levels of service and at all times of service provision.

(3.12.8) States should take advantage of funding opportunities to provide language access services. For example, the Centers for Medicare & Medicaid Services (CMS) allows states to include language services as an optional service in their Medicaid and State Children's Health Insurance Programs (SCHIP), in order to reimburse providers directly for the costs of these services for program enrollees.

(3.12.9) NAMI calls for funding, development and implementation of mental health education and awareness campaigns that specifically target diverse communities and for culturally competent prevention and early intervention initiatives.

(3.12.10) NAMI calls for funding, development and implementation of efforts to increase the diversity of the nation's mental health workforce, including peer support, and the strengthening of cultural competent skills of the nation's existing mental health service delivery providers.

3.13 Wellness

(3.13.1) People living with serious mental illnesses are at significantly greater risk for other serious medical illnesses such as diabetes, heart disease, cancer, and respiratory diseases, as well as AIDS and Hepatitis C. Recent research indicates that they also have much shorter life spans, as much as twenty-five years less than other Americans. This disparity has increased over time and demands increased attention and funding to promote wellness and preventive awareness among people with serious mental illness, their families, and health care practitioners.

(3.13.1.2) Persons Infected with the HIV Virus and/or Hepatitis C

NAMI believes that all persons with serious mental illnesses should be encouraged to be tested for HIV and Hepatitis C. NAMI believes that persons who test positive should receive

appropriate treatment for both their serious mental illnesses and the Hepatitis C and/or HIV-related illnesses in the least restrictive setting that is safe for all concerned. The results of testing should be shared only on a "need to know" basis and should include families and others who serve as primary caregivers primary caregivers. If families are not primary caregivers, persons with serious mental illnesses should be encouraged to share this information on a voluntary basis.

Persons with serious mental illnesses living in institutional settings have been identified as high risks for these infections. Therefore, NAMI believes that all persons with serious mental illnesses in institutional settings should be offered testing and strongly encouraged to participate in testing.

NAMI urges that education, counseling, and peer support should be made available to the person with a serious mental illness who tests HIV or Hepatitis C positive and, whenever possible, should be offered to their family and staff as well.

(3.13.1.2) Persons Living with Other People Who May Be Infected with the HIV Virus and/or Heptatitis C

All person living in group housing or residential settings where the health status of other house mates may or may not be known should be taught to practice safe living habits. They should be taught how infectious diseases are transmitted. All housemates should be taught methods to prevent transmission of serious infectious diseases between each other regardless of their relationship.

(3.13.2) Wellness is essential to treatment and recovery. Consumers, family members and providers should promote and encourage wellness. Wellness encompasses mind, body and spirit. Wellness should include nutrition, exercise, rest, dental care, physical exams, and tobacco, drug and alcohol cessation.

(3.13.3) People living with serious mental illness have the same rights and expectations as anyone else to lead healthy lives. Wellness is an important part of the recovery process. Consumers must be empowered to achieve wellness through consumer education and peer support and taking control of their own health and recovery.

(3.13.4) Providers must make wellness a priority and provide access to effective programs and exercise. Useful programs include, but are not limited to, nutrition counseling, cooking classes, exercise programs, yoga, breathing exercises, smoking cessation, drug and alcohol programs, walking trails, exercise equipment at mental health centers and drop in centers, membership in gyms, and appropriate monitoring. Those who provide meals must ensure nutritious choices, including fresh fruits and vegetables. Those who provide treatment must be aware of and actively engaged in supporting wellness; and those who provide supportive environments, including housing and clubhouses, must provide environments that reduce health risks and support overall wellness.

(3.13.5) People with serious mental illnesses must have access to effective prevention and treatment with respect to alcohol, drug and tobacco addiction.

(3.13.6) NAMI calls for better access to dental care. Because of the impact of mental illnesses and the effects of the medications used to treat serious mental illnesses, access to dental care is a particularly important part of wellness for individuals with serious mental illnesses.

(3.13.7) NAMI also calls for better integration of physical and mental healthcare, including sharing relevant health indicators. Mental health care providers need to monitor key physical health indicators and the physical effects of medications. Primary care doctors must follow up on physical issues identified. There must be better infrastructure and funding to process important screening labs and tests for individuals with serious mental illnesses.

(3.13.8) The federal and state governments should provide fiscal incentives for integration of mental, physical and dental health services and funding for successful wellness programs. State programs that seek to reward healthy behaviors must be positive, relevant to individuals with serious mental illness, and not punitive in nature.

(3.13.9) Wellness is an important investment that will lead to decreased public cost, improved resource allocation, and reduction in stigma, thus improving the lives of all those affected by serious mental illnesses.

4. Services and Supports for Children, Adolescents, Young Adults and Families

NAMI advocates for research and services in response to major illnesses that affect the brain, including schizophrenia, schizoaffective disorder, bipolar disorder, major depressive disorder, obsessive-compulsive disorder, panic and other severe anxiety disorders, borderline personality disorder, post traumatic stress disorder (PTSD), autism and pervasive developmental disorders, and attention deficit/hyperactivity disorder.

4.1 Comprehensive Array of Services and Supports

A comprehensive array of treatment, services and supports that address prevention, early intervention, recovery, and support should be available to children, adolescents and young adults living with mental illnesses and their families. These services should be available through publicly and privately funded service systems. They should promote resiliency and recovery and include evidence and research based interventions. There must be effective system coordination and collaboration between systems serving children, youth, young adults and their family.

Services, supports and appropriate accommodations should always be timely, easily accessible, and provided in the least restrictive environment.
They should include, but not be limited to:

- Services provided in the home and community;
- Intensive case management;
- Crisis intervention services;
- School-based services;
- Wrap-around services;
- Respite care;
- Therapeutic mentoring and recreation programs;
- Family education and support programs;
- Vocational and rehabilitative services; and
- Inpatient and residential treatment.

Peer support services should be available at all times and at all levels of care.

States and communities should invest in home and community-based services as the primary treatment modality. Children should not remain in inpatient and residential treatment beyond the time of planned therapeutic benefit.

4.2 School and Campus Based Services

Schools must protect the confidentiality of all students' mental health related information.

All schools, including institutions of higher education, should understand and follow federal and state privacy laws for both health information and education information and their responsibility for appropriately addressing the needs of students with mental illnesses and psychiatric emergencies under those laws.

(4.2.1) Elementary, Middle and High Schools

Undiagnosed, untreated, and inadequately treated mental illnesses significantly interfere with a student's ability to learn, to grow, and to develop.

Because children spend much of their productive time in school and services can be integrated into their regular daily routine, NAMI believes that both public and private elementary, middle and high schools should provide and/or facilitate and sustain provision of appropriate mental health services, supports, and appropriate accommodations.

In order to assure that coordination of services can be supported and maintained and that families have adequate resources to address their needs, schools should maintain a close connection to the community mental health and primary health care systems. The caseload of school-based mental health providers should be capped at a level that ensures that they can adequately address the needs of students and their families.

School systems should be adequately funded to provide special education services and to meet the academic and functional needs of all students with brain disorders. This will require access to both public and private funding for mental health services and supports. All students should receive an education in the least restrictive setting and in general education classrooms unless their needs can only be met, and are better addressed, in a separate or alternative classroom.

The bullying that currently exists in far too many of our nation's schools disproportionately hurts students with disabilities, especially those living with mental illnesses. All schools should develop effective anti-bullying policies so that students with mental illnesses are not targeted by bullies or labeled as bullies as a result of symptoms of their mental illness.

(4.2.2) College and University-Based Services and Supports

NAMI believes that colleges and universities should provide a full array of services, supports and appropriate accommodations for both campus-based and commuting students. The array should include mental health evaluations, outpatient treatment, peer support specialists, integrated services for co-occurring brain and substance use disorders, on-campus support and information sources and referrals, a link to the community mental health and crisis intervention service systems, and 24 hour urgent care available daily. In no case should a student be penalized by dismissal

or probation or be denied the right to enroll in a course of study solely because of a mental illness.

Support, education, and advocacy programs should be available and accessible for students and their families on college and university campuses. Colleges and universities should include comprehensive information about mental health treatment, services, and supports on their web sites and should notify students and their families about the availability of this information. They should also share information about the early warning signs of mental illnesses and develop effective suicide prevention plans responsive to the high incidence of suicide in young adults aged 15 to 24.

If a student experiences a psychiatric crisis, the college or university should immediately contact the student's family about the crisis. Colleges and universities should never use the existence of a psychiatric crisis as grounds to ask a student to leave the school. Instead, schools should develop appropriate accommodations and supports that appropriately address the needs of students experiencing a psychiatric crisis or recovering from a psychiatric crisis.

4.3 College and University-Based Services and Supports

(4.3.1) NAMI advocates that colleges and universities provide an effective and accessible array of mental health services, supports and appropriate accommodations for both residential and commuting students. Mental health services and supports should be integrated with other health services in order to improve overall wellness and prevent stigma that may be associated with separate mental health services and facilities.

(4.3.2) Mental health services for college and university students should include, but not be limited to, the following:

- Screening and evaluation;
- Walk-in health facilities;
- Individual and group therapy and counseling;
- Peer support specialists and peer run support groups;
- Integrated services for mental illnesses and substance abuse disorders;
- Easily accessible information about mental illnesses, including referral to off-campus treatment, services and support;

- Convenient links to community mental health services, including crisis intervention;
- Widely publicized availability of a 24-hour, seven day a week hot-line connected with urgent care;
- Access to psychiatric care whenever in the best interests of the student and medication management; and
- Training for campus law enforcement and other first responders, such as CIT and other approaches.

(4.3.3) Students should not incur financial loss, loss of housing or other available student services, or dismissal, probation or denial of enrollment in a course of study, class or activity solely because of mental illness. Reasonable and individually appropriate accommodations must be made available to students with mental illnesses, including during periods of crisis and recovery from crisis.

(4.3.4) Support, education and advocacy programs should be available and accessible to students on college and university campuses. Colleges and universities should welcome the organization and operation of Mental Health First Aid, NAMI on Campus Clubs and NAMI peer and family support programs, other student led peer activities, and programs that raise awareness about mental illnesses, help students to manage stress and avoid isolation, maintain overall wellness, support students living with mental illnesses and eliminate all forms of stigma that may be barriers to students seeking information, treatment and access to services. Such programs should include family involvement for students who are legal dependents, married, civil partners or who otherwise seek family involvement.

(4.3.5) Colleges and universities need to include accurate and reliable information about mental illnesses and mental health treatment, services and supports on campus-hosted websites and, with effective privacy warnings, in other campus-hosted social media. Such information should include advice on prevention, awareness of the early warning signs of mental illnesses and how students may seek help for themselves and others. Campus-sponsored disability resource centers, campus administrators responsible for compliance with accessibility requirements for people with disabilities, and campus sponsored student health services must be staffed by people trained to understand mental illnesses, appropriate accommodations and treatment. Information about mental health and mental health services, supports and accommodations should be made available during orientation for new students and their families.

(4.3.6) Colleges and universities should employ mental health professionals who are trained to provide effective services and supports that include meeting the often diverse needs of students in terms of age, family status, gender, race, ethnicity, language, sexual orientation and status as veterans. Such training must include awareness of best practices and emerging practices as well as the importance of family and peers to recovery and resilience for students and for young adults in crisis or living with mental illnesses.

(4.3.7) Colleges and universities need to develop and publicize institutional policies and practices that protect confidentiality and privacy related to mental health treatment and services. Such policies and practices need to be publicized, understandable and followed. Consistent with applicable federal and state law, students and families must be clearly informed about the circumstances in which colleges and universities may contact family members or mental health caregivers in connection with emergencies or other urgent circumstances involving the health and safety of a student or others. Students who may be experiencing the onset of a mental illness or living with mental illness should be counseled about the benefits of consenting to sharing information with their families and mental health caregivers.

(4.3.8) Effective suicide prevention plans and practices must be in place at colleges and universities in order to respond to the high incidence of suicide in young adults under 24 years of age.

(4.3.9) Federal, State and private funding should be better coordinated and integrated in order to provide services and supports for college and university students with mental health issues.

4.4 Restraints and Seclusion in Schools

The use of restraints and seclusion in schools -- causing trauma, injury and death in far too many cases -- disproportionately impacts students with disabilities, most often students with mental illness.

Restraints refer to the forced restriction or immobilization of a child's body or parts of the body to control behavior. Escorting and the immediate physical separation of children in conflict are not considered a restraint. *Seclusion* is involuntary confinement in a room, box, structure or space from which a child cannot leave. Seclusion does not include requiring a child to leave an activity, to move to a quieter or less stimulating location, or to be in a comfortable unlocked room designed to reduce stimulation or anxiety and from which the child could come and go.

NAMI believes that restraints and seclusion should not be used in our nation's schools except in emergency circumstances as described below. NAMI calls for the enactment of federal and state legislation and the adoption of regulations to address the following issues related to the use of restraints and seclusion in our nation's schools:

(4.4.1) Authorize the use of federal Title I education funds and provide additional federal funding to implement Positive Behavioral Supports (PBS) and require as a condition for funding that schools implement positive, evidence-based plans and procedures for all students who exhibit behaviors that interfere with learning or that may threaten to place themselves or others in imminent danger;

(4.4.2) Develop federal standards and provide additional federal funding for training in restraints use, prevention and reduction and require all staff to be trained within the first month of each school year on the school's emergency and crisis prevention procedures, de-escalation to help avoid crises, and debriefing procedures. Require that school staff receive training and demonstrate competence in the following areas: the early warning signs of mental illness and effective crisis intervention for students with mental illnesses; positive behavioral supports and interventions; communicative intent of behaviors; relationship building; alternatives to restrictive procedures and identifying events and environmental factors that may escalate behavior; de-escalation methods; obtaining emergency medical assistance; the physiological and psychological impact of restraints and seclusion; and the skills that students need to better regulate and manage their behaviors;

(4.4.3) Prohibit the use of restraints except in emergency cases defined as those involving an imminent risk of danger to the child or adolescent or others and no other safe, effective intervention is possible. Restraints may only be used by staff who have received intensive training and with rigorous supervision and must cease as soon as the emergency ends. Prohibit the use of any form of restraint that interferes with breathing and/or the ability of students to speak or otherwise communicate, e.g., prone restraints (with the student face down on his or her stomach), supine restraints (with the student face up on the back), or any maneuver that places pressure or weight on the chest, lungs, sternum, diaphragm, back, neck, or throat.

(4.4.4) Prohibit the use of seclusion except in emergency cases defined as when a child must be physically separated from others because of an imminent risk of danger to an individual or others and when it has been documented

that no other safe, effective intervention is possible. The child must be released from seclusion the moment the emergency ends. The room used for this purpose must be designed to provide a safe and non-threatening environment. The door to the room may not be locked, but it may be temporarily held closed with a device that requires a staff person to hold it in place and to see and hear the child at all times. Staff must be able to visually and audibly monitor the child at all times. Occasional checks are not acceptable. If a child is secluded for more than 15 minutes, either the school principal or an administrator responsible for the school in the absence of the school principal, must personally observe the child and note any reason for continued seclusion in a log maintained for that purpose. The school principal or administrator responsible for the school in the absence of the school principal must renew these observations every 15 minutes until the child is released from seclusion; and immediately attempt to notify the family of any continuous seclusion exceeding 15 minutes;

(4.4.5) Require that whenever there are multiple applications of restraints and/or seclusion, or whenever recurring use of restraints and/or seclusion is likely, a meeting must be promptly convened with the student's teacher, the school principal, the student's family, a mental health provider, and other relevant school staff to identify the circumstances leading to the use of restraints or seclusion and to discuss the appropriateness of a Section 504 plan or an Individual Education Program (IEP);

(4.4.6) Prohibit disciplinary techniques or behavior interventions that compromise the health and safety of students and others; cause physical or psychological injury, harm or are demeaning; or deprive students of basic human necessities or rights - including food, hydration and bathroom visits;

(4.4.7) Provide that restraints and seclusion are not to be used as a means of punishment or as a response to property destruction, disruption of school order, refusal to comply with school rules or directives, or in response to verbal threats that do not constitute an imminent danger to self or others;

(4.4.8) Prohibit the inclusion of restraints and seclusion in a student's individual education plan (IEP) or as part of a student's behavior intervention plan (BIP);

(4.4.9) Provide all students with a range of programs to prevent behavioral emergencies, including mental health services, anti-bullying programs, social problem-solving programs, positive skills development, and related

services. In the event of an emergency and whether or not restraints or seclusion were employed, all students should also be offered relevant services including but not limited to mental health services, trauma informed care, counseling and related services;

(4.4.10) Require that parents and caregivers be informed immediately of all emergency interventions and incidents of restraints or seclusion occurring that day that involve their child. This is necessary in order to ensure that parents and caregivers can exercise their right to meaningful participation in the development of safe and positive interventions and supports for their child as well as being assured that action will be taken immediately to help avoid similar events in the future. If the school is unable to immediately reach parents or caregivers to inform them about the emergency use of restraints or seclusion, then the school must document attempts made to reach them;

(4.4.11) Require schools to provide clear procedures for school staff to report perceived abuse with respect to restraint and seclusion and ensure that parents and caregivers are aware of all available legal remedies, including the right to pursue legal action;

(4.4.12) Require schools, using uniform reporting standards, to collect data on the emergency use of restraints and seclusion in schools, including the identity of all school staff involved in these incidents. These data must be collected by State Education Agencies and should also include the number of times restraints and seclusion are used, the duration of usage, the emergency circumstances that led to their use, the ages of the students, injuries to students (as reported by school staff and parents), the identity of all school staff involved in the use of restraints and seclusion in schools and fatalities. Incident reports summarizing these data should be provided to parents, caregivers and providers. These data should be available to the public and used by the U.S. Department of Education to target action to reduce restraints and seclusion. This action should include training, technical assistance, and corrective action related to any inappropriate use of restraints and seclusion.

(4.4.13) Require that each state annually develop a publicly available report on efforts targeting the elimination of the unnecessary use of restraints and the elimination of seclusion and efforts to create a more positive school climate and culture; and

(4.4.14) Intervention by law enforcement personnel is not acceptable as an alternative to the use of restraints and/or seclusion.

4.5 Transition Age Services and Supports

NAMI urges the development of effective services that bridge the transition from child to adult for youth living with mental illnesses. These services should be available in our nation's schools and they must be provided by appropriate community agencies such as post secondary institutions, vocational rehabilitation agencies, housing agencies and other agencies, as appropriate. Planning for appropriate transition services should begin, at a minimum, by age 14 and should continue as adolescents progress into adulthood. Barriers to a smooth transition from adolescence to adulthood or to the delivery of effective transition services, such as the imposition of financial criteria or program eligibility requirements, must be eliminated.

4.6 Educational Programs

(4.6.1) NAMI believes that a transformed system of care must be focused on resiliency (increasing protective factors in a child's life, helping to ensure early identification and intervention, and a child's ability to bounce back from adversity) and recovery and driven by consumers and families. A transformed system must also guarantee the widespread availability of free mental health educational programs for children and adults living with mental illnesses and families at every stage of the life cycle, and must empower them to be teachers in the education and training of all mental health providers.

(4.6.2) Peer-designed and peer-directed educational programs, at every stage of the life cycle, must be valued and promoted as an integral part of the service system. Specific government grants must be made available to support the development and administration of peer-directed programs. In addition, system resources must be made available to develop and evaluate peer educational programs and to establish an evidence base comparable to the rigorous scientific studies conducted by fully funded system-based programs.

4.7 Training and Qualifications for Providers

NAMI calls for all child-serving professionals to receive training that will help them better understand early onset mental illnesses and how to communicate effectively with families about these illnesses. Healthcare providers treating children and adolescents with mental illnesses should receive as much training as

necessary to ensure that they can and will provide evidence and research based treatments and service interventions.

4.8 Integrated Health and Mental Health Care

NAMI calls on policymakers, providers and public and private funders of healthcare services to place a high priority on addressing the critical need for integration of physical and mental health care. The causes of health and disease are a product of the interplay or interaction between biological, psychological, and socio-cultural factors. This is true for all health and illness, including mental health and mental illness.

Primary care and mental health care providers working with families, youth and young adults living with mental illnesses, should make a commitment to ensure that adequate time, training, and resources necessary to provide appropriate care for children, youth and adults living with mental illnesses are available and accessible when and where they are needed. They can accomplish this through collaborative practice arrangements, interagency system coordination, and interdisciplinary teamwork. The integration of physical and mental health care produces better treatment outcomes and overall better health outcomes for children, youth and adults living with mental illnesses.

NAMI believes that it is critically important that primary care providers be trained and qualified to recognize the early warning signs of mental illnesses, and to screen and evaluate children for mental health treatment needs. Because children and families often visit primary care providers as part of well-child clinical care, this is an important opportunity to identify a child's need for mental health related treatment and services, at the earliest possible time.

4.9 Family Driven and Youth Guided Services

All services and supports provided to children living with mental illnesses and their families should be youth guided and family driven, with the needs of the child and family dictating the types and mix of services provided. (see section 3.6 on Family Involvement in Treatment)

5. Services and Supports for Adults

5.1 Community Systems

(5.1.1) NAMI believes that it is the responsibility of government at all levels to develop and maintain comprehensive community support systems that

include treatment and services, as well as short-and long-range plans, for all adults with serious mental illnesses.

(5.1.2) NAMI believes optimal treatment, favorable outcomes, and recovery are most likely to occur when comprehensive treatments and services are provided in an atmosphere of respect, acceptance, and hope.

(5.1.3) NAMI believes that all publicly funded community service providers must offer evidence based, promising and emerging practices and services that adults living with serious mental illnesses need. These practices and services must be recovery, resiliency and wellness oriented, culturally competent and readily accessible. These practices and services must include the availability of appropriate and effective medications, inpatient treatment, and outpatient treatment with mobile capacity, residential support services, transportation services, intensive case management, respite services, vocational and psychosocial rehabilitation, peer support, consumer-run services, and round-the-clock services that are available seven days a week.

Service providers must prioritize access to services to people with serious mental illnesses, providing oversight and advocacy through well-trained care managers. Services should use an integrated consumer-centered approach that may take professionals out of the traditional office setting to a location that is comfortable for the consumer. Treatment should be delivered at the same treatment site using cross-trained staff.

(5.1.3.1) NAMI endorses integrated, rather than sequential or collaborative-parallel treatment programs for persons with co-occurring serious mental illnesses and addictive disorders treatment delivered at the same treatment site using cross-trained staff.

5.2 Continuity of Care

(5.2.1) Every consumer should have a single service manager or management team that is well informed about every aspect of the treatment and informs the consumer and other members of the treatment team. When an individual is hospitalized, the manager should be kept informed and should become a member of the inpatient treatment team. Whenever residence in a community is interrupted for any reason, continuity of care requires that the same service manager or management team retain responsibility for an individual's treatment unless the consumer desires a change.

5.3 Community Housing

(5.3.1) Housing is critical to recovery and should be immediately available to sustain treatment, resiliency, recovery and community for people with mental illnesses. People with serious mental illnesses especially need a wide array of options for decent, affordable housing based on individual needs and choices.

(5.3.2) NAMI supports housing choices for people with mental illnesses that include rental or ownership in independent living, supportive housing and group homes that include the availability of wrap-around services, other support and, when appropriate, education about maintaining living in and financing of housing. Based on individual needs and choices, living independently in the community should be given priority. Funding, services and support should follow the person with respect to all housing choices, including housing provided by care-givers. Available, affordable housing choices should also facilitate access to education, employment, transportation and other needs of daily living.

Federal, state and private financing of housing for people with mental illnesses should be better coordinated and integrated in order to link housing development with operating funds and funds for treatment, services and other support.

(5.3.4) NAMI opposes legal restrictions on housing that discriminate in location, limit and equal access, segregate, prevent family preservation or deny choices in occupancy or living arrangements solely on the basis of mental illness, including people who are seeking treatment or are in recovery from co-occurring substance abuse. Families must not be expected to be legally responsible for or pay for the costs of providing housing for adult family members with mental illnesses who are not legal dependents. No one with a mental illness should be housed in a nursing home and similar long-term care facility without an independent determination of a geriatric or other appropriate medical condition.

(5.3.5) NAMI affirms that persons living with mental illnesses have no less rights to dignity, privacy, security and stability in their living arrangements. People with mental illnesses should not be at risk of losing housing in the community during periods of crisis, hospitalization or inpatient treatment.

5.4 Education and Employment

(5.4.1) NAMI believes that people living with mental illnesses want, need and have the right to be meaningfully employed, including continuation and advancement on the job, in chosen professions and in businesses. Yet unemployment and under-employment rates are higher among persons with mental illnesses and result in undue reliance on public assistance.

(5.4.2) NAMI advocates full and fair access for people with mental illnesses to education, continuing education, vocational rehabilitation, training, professional development, personal development, employment, business and business assistance. Federal and state education, workplace rights, employment opportunity and worker's compensation laws as well as business assistance must fully and effectively protect against stigma and all discrimination on the basis of mental illness. Disincentives to employment in Medicaid, Medicare and other federal or state programs that help fund treatment and support for people with mental illnesses must be eliminated.

(5.4.3) NAMI believes that people with mental illnesses must have the opportunity to be actively involved and supported in making personal choices related to education, training, employment, entrepreneurship and business development.

(5.4.4) NAMI urges employers to offer a variety of workplace options, including on-the-job personal and peer assistance, education, training and professional development as well as transitional employment, flextime and telecommuting that may be especially helpful to people with mental illnesses. Training should also be provided to managers, supervisors and other employees to raise awareness about maintaining a supportive workplace for people with mental illnesses.

(5.4.5) NAMI seeks effective cooperation and collaboration among public agencies, not-for-profit agencies, health care providers and insurers as well as family members and peers of people with mental illnesses in integrating and evaluating the most effective delivery of treatment, wellness, vocational rehabilitation, education, training, professional development, employment services, supported employment, transitional employment, business assistance, transitional services, family services and continuing support for people with mental illnesses entering, in and re-entering the active workforce.

(5.4.6) NAMI asks that federal and state labor agencies effectively measure, track and report unemployment rates among people identified as living with psychiatric disabilities.

(5.4.7) NAMI supports the development of effective recruitment and training of people with mental illnesses for employment and careers related to mental health care and support for persons with mental illnesses.

5.5 Consumer-run Programs

NAMI supports and encourages self-help activities and consumer-run programs including peer support, housing, day centers, small businesses, clubhouses, and drop-in centers. NAMI also supports and encourages all service providers to support the development of such self-help activities.

5.6 Educational Programs for Consumers and Families

(5.6.1) NAMI believes that a transformed and recovery, resiliency and wellness oriented system of care, driven by consumers and families, must guarantee the widespread availability of free educational programs for consumers and families, and must also empower consumers and family members as teachers in the education and training of all mental health care providers.

(5.6.2) Peer-designed and peer-directed educational programs must be valued and promoted as an integral part of the service system. The development and administration of peer-directed programs must be supported through specific public funding and further system resources must be made available in order for peer educational programs to be strongly evidence based.

6. Financing of Treatment and Services

6.1 Health Care Reform

(6.1.1) NAMI supports health care for all persons with mental illnesses that is affordable, nondiscriminatory, and includes coverage for the most effective and appropriate treatment.

(6.1.2) NAMI supports equal access to affordable health care for every American.

(6.1.3) NAMI supports mandatory coverage and full parity for mental illnesses that is equal in scope and duration to coverage of other illnesses, without

lifetime maximum-benefit caps and other limits more restrictive than those required for other illnesses or disorders, and covers all clinically effective treatments appropriate to the needs of individuals with mental illnesses.

(6.1.4) While NAMI supports federally mandated, minimum standards for health insurance coverage, federal standards must not pre-empt state laws that provide higher standards.

(6.1.5) NAMI believes that all insurance plans, whether based on employment in the private sector, employment in the public sector (including federal, state and local governments), available through membership in unions, or individually purchased, must cover mental illnesses and addictive disorders at parity with all other medical disorders. These parity requirements must apply both to quantifiable treatment limitations (for example, premiums, co-pays, deductibles, annual limits, lifetime limits, etc.) and non-quantifiable treatment limitations (for example, medical management standards, utilization review practices, formulary designs for prescription drugs, etc.). NAMI strongly opposes all exceptions to these parity requirements.

(6.1.6) NAMI opposes health care rationing.

(6.1.7) NAMI urges federal and state standards that make any determination of "medical necessity" by a consumer's primary mental health care provider a presumption rebuttable only on the basis of clear and convincing independent medical evidence.

(6.1.8) NAMI believes that treatment and care for all consumers requires a documented diagnosis, an individual treatment plan with clinical goals and documentation of progress, and that mental health care providers are properly licensed, certified, or recognized by the state and meet national standards for clinical care.

6.2 Public Responsibilities and Resources

(6.2.1) NAMI affirms that a just and humane society, using the instrument of government for policy direction and public resources allocation, must care for its most vulnerable members when they are unable to care for themselves. Essential needs must be addressed irrespective of decisions concerning what level of government should have control, what proportions of the financing each level of government should be

responsible for and whether administrative, supervisory or other responsibilities are contracted out privately.

(6.2.2) Persons of all ages who suffer from serious mental illnesses are frequently unable to provide for themselves because of acute or chronic symptoms. The most basic needs are for shelter, food, clothing, medical and social supports, and assistance toward self-sufficiency. All levels of government must address such needs by providing programs for income maintenance, medical treatment and a full range of psychotherapies, rehabilitation, and evidence based treatments for mental illnesses, medical insurance, other health and social services, shelter and housing, education, transportation assistance, legal assistance, advocacy, training, and employment assistance.

(6.2.3) Government at all levels must oversee, assist and encourage the fullest possible integration of public and private resources into an effective and sustainable system of mental health care at all levels.

6.3 Medicare

(6.3.1) Medication prescribed for the treatment of serious mental illnesses must be fully covered under the Medicare prescription program.

(6.3.2) Co-payments imposed on outpatient mental health care and services must be equalized with all other Medicare co-payments.

(6.3.3) There should be no lifetime limit in Medicare on inpatient psychiatric hospitalization. Coverage of inpatient and outpatient mental health treatment and services should be equal to all other inpatient and outpatient treatment and services in Medicare.

(6.3.4) NAMI advocates for coverage of psychiatric rehabilitation, case management, assertive community treatment and other evidence-based mental health services in Medicare. (RH 3-3-2010)

(6.3.5) NAMI supports coverage of partial hospitalization under Medicare but believes that this benefit must be structured to cover services that are rehabilitative and intended to restore functioning or improve functioning to enable recipients to live safely and as independently as possible in the community. (RH 3-3-2010)

(6.3.6) Any risk adjustment payment mechanism under Medicare must include consideration of both severity and chronicity of mental illness.

(6.3.7) Social Security Disability Insurance (SSDI) recipients who seek work should be allowed to continue Medicare insurance coverage and persons who go off Medicare because they have obtained employment should be automatically re-enrolled in Medicare in the event of a subsequent clinical relapse.

(6.3.8) Medicare must include comprehensive patient protections that are the same as any other health care coverage.

6.4 Public Financing

(6.4.1) NAMI recognizes that the cost of not treating serious mental illnesses vastly exceeds the cost of treatment.

(6.4.2) Financing services for persons with serious mental illnesses who are unable to care for themselves is a public responsibility. Governments at all levels have a responsibility to develop an integrated system of care that is funded sufficiently, effectively and efficiently.

(6.4.3) Meaningful accountability for expenditure of funds for programs and services to persons with serious mental illnesses must be ensured and especially stringent whenever there is co-mingling of public and private funding.

(6.4.4) NAMI urges sufficient and sustained funding to avoid waiting lists and "dumping" of persons with serious mental illnesses from publicly funded mental health care for any reason.

(6.4.5) NAMI advocates for sufficient and sustained funding for biomedical and service research related to serious mental illnesses and for treatment and services for individuals with serious mental illnesses. These research funds must be awarded to those proposals most likely to help persons with the most severe disabilities and federal oversight of this research funding must be effectively maintained by appropriate national institutes responsible for health research and development with respect to serious mental illnesses.

(6.4.6) NAMI supports consumer and family education - that enables consumers and families to communicate more effectively with providers, better understand serious mental illnesses and develop coping skills. NAMI

believes that - consumer and family education should be provided without charge as an integral part of community services.

(6.4.7) NAMI supports funding for respite care.

(6.4.8) NAMI will monitor the expenditure of federal mental health care funding at all levels of government in order to assure that these funds are spent to benefit individuals with serious mental illnesses and that non-compliance results in appropriate sanctions

(6.4.9) NAMI opposes restrictions on Medicaid eligibility solely based on residence in so-called "Institutions for Mental Diseases" (IMDs) or otherwise solely on the basis of place of residence or location of services provided rather than need.

(6.4.10) NAMI believes that resources saved as a result of closing public hospitals and other facilities no longer necessary for the treatment of persons with serious mental illnesses, reduced utilization of such hospitals and facilities, or through service improvements and efficiencies should be reallocated supplementally to expand community-based services and supports for persons with serious mental illnesses.

(6.4.11) NAMI supports the integration of mental health, alcohol and substance abuse funds at all levels of government in order to improve the effectiveness of treatment for co-occuring disorders of serious mental illness and substance abuse.

(6.4.11.1) NAMI urges governments at all levels to assure that basic services provided to persons with developmental disabilities are also provided to persons with mental illnesses; supports the inclusion of mental illnesses in the scope of developmental disabilities planning and funding; and promotes effective collaboration between the Center for Mental Health Services and the Administration on Developmental Disabilities; and between each State Mental Health Planning Council and State Planning Council on Developmental Disabilities.

6.5 Managed Care

(6.5.1) Governments at all levels must continue to have authority over and be accountable for the delivery of treatment and services for persons with

serious mental illnesses when contracting out treatment and services to private managed care organizations (MCOs).

(6.5.2) NAMI believes that even when treatment and services are contracted out to MCOs, persons with serious mental illnesses who are employed but cannot obtain employer-provided health care coverage should continue to be eligible for public health care benefits and government at all levels must maintain the availability of a comprehensive community-based system of treatment and services for persons with serious mental illnesses.

(6.5.3) There must be meaningful participation by consumers and families in the design, implementation, monitoring and evaluation of managed care system as well as cultural sensitivity to ethnically diverse populations and communities.

(6.5.4) Whenever government at any level contracts with MCOs or other entities to solely manage or deliver Medicaid-funded services for persons with serious mental illnesses, there must be no resulting division within the overall mental health system that causes persons who are most severely disabled by serious mental illnesses and require the greatest use of more costly treatment and services to be carved out into less funded or less effective public mental health care systems.

(6.5.5) When contracting out to MCOs results in reduced public expenditures, the savings must be reinvested in expanding services to persons with serious mental illnesses.

(6.5.6) MCO administrators and treatment staff must be trained and expected to understand serious mental illnesses, work with persons with serious mental illnesses including awareness of the consumer and family perspective and accept accountability for the quality of services provided.

(6.5.7) All MCO treatment staff must be rigorously and appropriately credentialed by appropriate state agencies.

(6.5.8) MCOs must provide comprehensive community-support services available for persons with serious mental illness regardless of ability to pay and these services must include the availability of the most individually effective medications, talk therapy, inpatient treatment, residential support services, intensive case management, psychosocial rehabilitation,

consumer-run services, around-the-clock crisis services seven days a week and outpatient services that are mobile and accessible.

(6.5.9) MCOs must be accountable for appropriate and effective linkages to housing as well as supportive services and employment services.

(6.5.10) MCOs must be required to adhere to appeal and grievance procedures that are user-friendly and timely, given the life-threatening nature of psychotic episodes.

(6.5.11) MCOs must provide sufficient information and government at all levels must report at least annually on the number of persons with serious mental illnesses and other mental illnesses who 1) are identified but fail to present for services; 2) are in jail, prison or juvenile detention; 3) have been placed in a hospital, nursing home, or long term care facility; and 4) have died.

6.6 Fundraising by Non-Profit Agencies

(6.6.1) NAMI strongly encourages non-profit agencies serving persons with mental illness to engage in fundraising in order to diversify the sources of funding, augment services and raise community awareness.

(6.6.2) Governments at any level should not reduce funding to non-profit agencies serving persons with mental illness because the agencies have independently raised funds for services.

7. Research

7.1 NAMI's Support

(7.1.1) Neuroscience research, behavioral research, pharmaceutical research, clinical research, as well as service system research are some of the initiatives supported by NAMI. To this end, NAMI calls upon Congress and the Executive Branch to focus more attention on research, treatment, education, and rehabilitation related to serious mental illnesses and to appropriate funds sufficient to make that promise a reality. NAMI

supports both effectiveness and efficacy based research, focusing on severe and persistent mental illnesses, especially those with marked burdens of disease. NAMI expects the rigor and pace of the field of services research to be equal to that of biomedical research.

(7.1.2) Given the role culture plays in all aspects of mental health, it is imperative to focus more attention on culture specific mental health and substance use research. The National Institutes of Health (NIH) and its National Institute of Mental Health (NIMH) must increase funding for culturally specific mental health research, specifically in reference to persons of different ages and of varying cultures, racial, religious, ethnic, sexual orientation, gender, gender identity, and disability, including persons who are deaf and hearing impaired, and those for whom English is not the primary language. Particular attention must be given to areas such as epidemiology, psychopharmacology, diagnosis and assessment, prevention, evidence based practices, disparities, and cultural competence.

(7.1.3) Given the importance of evidence-based, promising and emerging practices in the current climate of mental health care, NAMI calls for the inclusion of diverse stakeholders in the development and testing of evidence-based practices (EBPs). To ensure quality of care for diverse communities, cultural competence must be defined and required for EBPs, and it should be incorporated into the development and implementation of existing and emerging EBPs.

The process of developing and credentialing EBPs needs to be modified to be inclusive of diverse communities and culturally competent community based practices. The process of implementing EBPs in these communities and with these specific populations must be supported with resources, including resources to document and test community based practices

7.2 Standards for Protecting the Well-being of Individuals Participating in Research

(7.2.1) NAMI accepts the critical necessity for research using human subjects, acknowledges the important contribution of persons who become human subjects, and affirms that all such research should be conducted in accordance with the highest medical, ethical, and scientific standards.

(7.2.2) National standards to govern voluntary consent, comprehensive exchange of information, and related protections of persons with cognitive

impairments who become research subjects must be developed and they must include the interests of persons who become human subjects, families, and other caregivers.

(7.2.3) Participants in research and their involved family members must be fully and continuously informed, orally and in writing, about all aspects of the research throughout the process. Research investigators must provide information in a clear, accessible manner to ensure that participants and their involved families fully understand the nature, risks, and benefits of the research.

(7.2.4) The consent protocol must provide clear and understandable information that is linguistically appropriate on an individual basis for each participant and the participant's family members. The consent protocol must provide information about the purposes and scale of the research, what is hoped to be learned, prospects for success, and potential benefits and risks to the individual (including options for treatment other than participation in research, since research is not the same as treatment). The consent protocol should also contain information about the function of the institutional review board (IRB), the identity of the IRB administrator, the address and telephone number of the IRB administrator and other information, as appropriate. The consent protocol and information for the subject and his/her family members should include a procedure for responding to medical and psychiatric emergencies. Research protocols should develop and implement a concrete plan to address these emergencies.

(7.2.5) Whenever consent is given by someone other than the research participant, the participant and involved family members must receive information on the same basis as the person actually giving consent.

(7.2.6) Research participants should be carefully evaluated before and throughout the research for their capacity to comprehend information and their capacity to consent to continued participation in the research. The determination of competence shall be made by someone other than the principal investigator or others involved in the research. Except for research protocols approved by the institutional review board (IRB) as minimal risk, whenever it is determined that the subject is not able to continue to provide consent, consent to continue participation in the research shall be sought from families or others legally entrusted to act in the participant's best interests.

(7.2.7) Research participants should be encouraged to develop psychiatric advance directives prior to beginning their participation in research protocols, indicating their research and treatment preferences should they become incapacitated at any point during their participation.

(7.2.8) Institutional review boards that regularly review research proposals for serious mental illnesses must include public participants who are consumers and family members who have direct and personal experience with serious mental illnesses.

(7.2.9) Members of IRBs approving research on individuals with serious mental illnesses must receive specialized training about serious mental illnesses and other cognitive impairments and the needs of individuals who experience these disorders. Persons with serious mental illnesses and members of their families must be integrally involved in the development, provision, and evaluation of this training.

(7.2.10) Without penalty, a research participant must be free to withdraw consent at any time, with or without a stated reason. Any time a participant terminates participation, regardless of the reason, investigators will make every effort to ensure that linkages to appropriate services occur with follow-up to assist that participant to establish contact with appropriate service providers and/or care-givers in a timely manner. If a participant disappears or terminates his or her continued consent, the investigator shall contact his or her family or others designated to receive notification and information.

(7.2.11) When participation by an individual in a research protocol is completed, participants and/or their families are entitled to be informed of results as soon as this information is available, to have the opportunity to receive feedback concerning their individual participation in the protocol, to critique the protocol, and to provide input concerning possible additional research.

(7.2.12) All participants in research protocols involving the assessment of new medications will be provided with opportunities by the investigator for a trial on the medication being studied, so long as other research on the new medication has demonstrated potential safety and efficacy.

(7.2.13) All individuals who have benefited from the administration of experimental medications in research will be provided continual access to the medication by the investigator without cost until a source of third-party payment is found or until the medication is approved for use.

7.3 Biomedical Research

(7.3.1) NAMI strongly encourages the donation of human organs and other tissue for transplant, research, and education, and the donation of tissue samples to developing gene banks. NAMI recognizes the severe shortage for research purposes of postmortem human brain tissue of persons who were afflicted with serious mental illnesses and members of their immediate families. All brain and tissue samples donated should be accompanied by appropriate clinical records.

(7.3.2) NAMI believes that the careful, responsible use of animals is indispensable in research on serious mental illnesses. At the same time, NAMI advocates the use of non-animal systems whenever feasible and urges researchers to observe the traditional, compassionate standards of animal experimentation; and to comply fully with the Federal Animal Welfare Act.

7.4 Psychopharmacological Research

(7.4.1) NAMI supports making psychopharmacological research a priority, given its impact on persons with serious mental illness and their families. Psychopharmacological research must include research on the efficacy of medications on populations of varying ages, genders, and varying racial and ethnic backgrounds.

(7.4.2) With Board review, NAMI may support legislation to place reasonable caps on product liability awards to encourage greater research and development.

7. 5 Disclosure of Potential Conflicts of Interest

(7.5.1) In order to maintain trust in the research endeavor, any situations that may create the appearance of a conflict of interest should be disclosed to potential participants in research. The source of funding for the research should always be disclosed.

(7.5.2) Examples of other required disclosures include:

- Investigators or institutions holding relevant stock or patent rights, serving as a paid advisor to the sponsor, or receiving direct or indirect honoraria from the sponsor for speaking about the class of products;

- Payments contingent on the number of subjects entering and/or completing the study, including payments made to recruiting firms or individuals;
- Investigators who also serve as the primary clinician (in which case the clinician/investigator should offer the opportunity of having an independent clinician involved in significant decisions.)
- Other individuals involved in the research or funding review process must disclose any vested interests they have in the research.

8. Quality Monitoring, Accountability, and Accreditation

8.1 Governing Boards

(8.1.1) NAMI recommends that at least 51 percent of the members of all public and private governing boards of organizations that make decisions or recommendations affecting the lives of persons with serious mental illnesses be Persons with serious mental illnesses, their families and friends.

(8.1.2) NAMI advocates that the Congress, state legislatures, and state executives require, through legislation and/or executive order, significant and meaningful consumer and family representation on, but not limited to, the following boards and councils: all policy-making boards and commissions having jurisdiction over private and public programs providing services to persons with serious mental illnesses, advisory councils for SAMHSA and the Center for Mental Health Services, State protection and advocacy boards and advisory committees, State mental health planning councils, State planning councils for developmental disabilities, and all governing bodies that regulate licensing and quality assurance in the private sector.

(8.1.3) While NAMI welcomes opportunities for consumers and family members to participate in task forces, study commissions, and advisory bodies related to the service delivery system for serious mental illnesses, NAMI does not consider such membership to be a substitute for full membership on governing bodies themselves.

(8.1.4) NAMI further urges associations of elected officials to similarly support such representation. While the appropriate number of such representatives will vary depending upon the function, purpose, and size of individual governmental and private entities, NAMI believes meaningful participation demands more than token representation. Therefore, such membership should be numerically adequate to assure an effective voice in

deliberations, equity and balance in relation to other family perspectives, and opportunity to impact significantly upon the outcome of deliberations.

(8.1.5) NAMI also encourages private sector care providers to include consumer and family representation on their governing bodies. Where financial hardship presents an impediment to full participation, funds should be provided to facilitate attendance at meetings.

(8.1.6) NAMI strongly encourages consumers and family members to seek appointments to, and to participate in, relevant governmental activities at the local, state, and federal levels, including service on general purpose governing bodies and the pursuit of elective office.

(8.1.7) NAMI urges its members to join institutional review boards that review current research studies and research grant committees as advocates for persons with mental illness, their families and friends.

8.2 Hospital Standards

(8.2.1) NAMI demands that admission, length of stay, treatment, and discharge policies of public and private hospitals must ensure that the basic rights of persons with serious mental illnesses are protected. NAMI requires that, upon intake, the results of a thorough physical and psychiatric examination be incorporated into an individualized treatment plan. These examinations should include a psychosocial history taken from available records, families, and significant others. An intake evaluation that fails to consider these records and resources is inadequate because such records may be helpful in determining patterns of illness.

(8.2.2) NAMI urges the state departments with regulatory authority to enforce the same hospital standards upon the private sector as stated above.

(8.2.3) The team that develops an individual treatment plan should include the consumer, the consumer's service manager, medical personnel, and, when appropriate, family members. As the consumer progresses, the plan must be changed as needed to include appropriate psychosocial rehabilitation, education, and pre-vocational skills training compatible with the combined goals of the consumer and the community. The hospital discharge plan must ensure adequate housing, medical care, and continuation of the individual treatment plan with community support services and a services manager. NAMI believes that the offer, payment, solicitation, or acceptance of a referral fee in relation to delivery of medical services is unethical.

8.3 Tobacco Addiction

(8.3.1) NAMI is committed to supporting in every way the wellness of people with mental illness and in recovery. NAMI recognizes that cigarette and other tobacco use is a dangerous form of addiction. Such addiction creates more significant health problems for people with mental illness and in recovery. People with mental illness and in recovery have the right to be smoke free and tobacco free. Effective prevention and treatment, including treatment of the effects of withdrawal, are available and should be part of effective mental health care treatment and recovery. People with mental illnesses must be given education and support to make healthy choices in their lives.

(8.3.2) Research shows that people with serious mental illnesses are twice as likely to smoke as the general population and that people with schizophrenia are three to four times as likely to smoke as the general population. The negative health effects of cigarette smoking and other tobacco use on personal health are well documented, including increasing risks of respiratory problems, cardiovascular disease, and certain forms of cancer. The negative health effects of exposure to "second hand" smoke are also well documented.

(8.3.3) Smoking has been inappropriately accepted and even encouraged in therapeutic settings for treatment and recovery. Access to smoking is sometimes used coercively and can be a source of disruption in treatment facilities. Smoking and other tobacco use also increase stigma.

(8.3.4) Therefore, NAMI supports and encourages smoke free and tobacco free environments in treatment and other health care facilities, group centers and common areas in housing, including prohibiting smoking and other tobacco use by health care providers, caregivers and others working in and visiting such facilities, centers and housing. NAMI opposes any practice that uses access to smoking and tobacco as a form of coercion or reward.

(8.3.5) At the same time, NAMI recognizes that the best time to provide and support smoking and other tobacco use cessation is not when consumers are in crisis because such treatment may exacerbate psychiatric symptoms and other conditions. Nicotine addiction is powerful and withdrawal is difficult for the general population, so it is particularly difficult for individuals experiencing a psychiatric crisis. Research indicates significant interactions of smoking and smoking cessation with certain psychotropic medications that can be improved through effective dosage regulation and

nicotine replacement. Research further indicates certain secondary, health issues associated with smoking and other tobacco use cessation, including weight gain, that require effective monitoring, counseling, peer support, self-help and treatment.

(8.3.6) Therefore, NAMI supports consumers in seeking smoking and other tobacco use prevention, cessation and recovery as essential to overall wellness in treatments and in programs available in the community. NAMI calls upon physicians and other health care providers, in community and inpatient settings, as well as group centers and programs, to implement educational and tobacco use cessation programs to help consumers stop and avoid tobacco addiction. Treatment and other facilities instituting smoke free policies must provide effective tobacco addiction treatment and support to consumers as well as health care providers, caregivers and others working in such facilities, who use tobacco products. Effective treatment and support must include:

(a) Smoking and other tobacco use cessation strategies and ongoing support;

(b) The most effective nicotine substitution products for individuals with nicotine dependence, as well as other medical approaches with proven effectiveness;

(c) Socialization, recreational and other structured activities;

(d) Counseling, peer support and other therapeutic supports;

(e) Careful assessment, monitoring and adjustment to medication regimens as appropriate; and

(f) Effective assessment, monitoring and assistance with respect to diet, nutrition and exercise to avoid weight gain and other common secondary effects of smoking and other tobacco use cessation.

(8.3.7) NAMI further supports incorporating tobacco usage in the definition of dual diagnosis; integration of mental health care and overall health care; more effective research at all levels on smoking, tobacco addiction and mental health treatment; and funding (including Medicaid and other public sources) to provide access to effective smoking prevention, cessation and recovery.

8.4 Deaths in Institutions

NAMI demands systematic reporting of deaths in institutions as an aid to improving quality of care. Deaths in psychiatric hospitals, correctional institutions, and other residential facilities can be important indicators of the quality of care provided to patients, inmates, and residents, especially when such deaths result from accident or suicide.

8.5 Protection and Advocacy Services

(8.5.1) NAMI supports federal laws that recognize the value of family and consumer representation on the governing bodies of protection and advocacy agencies, require protection and advocacy services in all treatment settings, allow for the filing of grievances against the priorities of a protection and advocacy agency, ensure family and consumer input into federal regulations, and provide for consumer and family training of staff.

(8.5.2) NAMI holds protection and advocacy systems accountable for protecting consumers from sexual and physical abuse while in hospitals and/or other facilities.

8.6 Training of Professionals

(8.6.1) NAMI believes that all professional and other providers who care for persons with serious mental illnesses need to be educated about these disorders and related, high-quality treatment and services. They must be sensitive to those affected. Staffing for facilities for persons with serious mental illnesses must be sensitive to the cultures and ethnicities being served.

(8.6.2) NAMI believes that there is a severe shortage of competently prepared professionals in all disciplines to treat persons with serious mental illnesses, particularly in low income communities or rural areas, or who can serve people of all diverse racial, ethnic, linguistic, disability and sexual orientation backgrounds. NAMI calls on the appropriate government agencies to provide new institutional grants to universities for facility development and recruitment of persons with culturally diverse backgrounds and those who have worked with persons with serious mental illnesses.

(8.6.3) NAMI supports federal budget expenditures for the clinical training of professionals that provide stipends to students in psychiatry, psychiatric

rehabilitation, psychiatric social work, psychiatric nursing, and psychology programs at the baccalaureate, masters, and doctoral levels. NAMI believes that all grants must include a pay-back provision for two-years of service in a public sector setting.

(8.6.4) NAMI asks that all academic curriculum and training programs preparing providers to serve persons of all ages with serious mental illnesses include knowledge based rehabilitation, recovery and resiliency models in the community, and attention to the development of compassionate, caring, and accepting attitudes towards consumers and their families.

(8.6.5) NAMI believes that all academic curricula and training programs, to be successful, must involve family members and consumers.

(8.6.6) NAMI requests that all pre-service training and continuing-education programs for providers be multi-disciplinary, culturally competent, and targeted toward the development of clinical expertise in working with under-served people, including elderly persons with serious mental illnesses, children and adolescents with serious mental illnesses, and adults disabled by serious mental illnesses.

(8.6.7) Fellowships must be provided to residents and junior faculty members in child psychiatry programs with adequate financial stipends for their training.

(8.6.8) NAMI identifies as an urgent priority the awarding of federal and state training grants for fellowships and stipends for advanced education of all professionals who want to specialize in the care of children with serious mental illnesses.

(8.6.9) Educational materials must reflect current knowledge about the treatment of serious mental illnesses. Professionals and other providers must understand and value recovery from mental illness and integrate its concept into their professional practice. All professionals serving persons with mental illness should encourage implementation of advance directives or healthcare proxies.

(8.6.10) Consumers and family members should be encouraged to participate in the educational process of professionals and other providers who treat or work with persons with serious mental illnesses.

(8.6.11) NAMI calls upon faculty of seminaries and schools of religion of all denominations to prepare clergy for service by including content about serious mental illnesses in their curricula.

(8.6.12) NAMI endorses an affirmative action policy for recruiting consumers with serious mental illnesses as students in educational programs that will prepare them for careers in the service delivery system.

8.7 Accreditation of Facilities and Programs

(8.7.1) NAMI urges that all facilities and programs serving persons with serious mental illnesses, including: hospitals, community mental health centers (CMHCs), clinics, day centers, psychosocial rehabilitation programs, vocational programs, community housing, correctional institutions (jails, prisons, and diversion programs), nursing homes, other institutions, and networks and programs seek accreditation. The accreditation process can be a means of avoiding at least some of the most conspicuous shortcomings all such facilities and programs might possess.

(8.7.2) NAMI also urges that all facilities and programs serving persons with serious mental illnesses should use vigorously the devices of periodic self-study with impartial, external review to seek continuously the improvement of their performance. The self-study process should include full participation of consumers and family members. Such participation as well as membership on the governing boards should be one standard for accreditation.
Such external review should include broad and convenient opportunities for confidential interviews with consumers and members of their families.

8.8 Use of Restraints and Seclusion

(8.8.1) The use of involuntary mechanical or human restraints or involuntary seclusion is only justified as an emergency safety measure in response to imminent danger to one's self or others. These extreme measures can be justified only so long as, and to the extent that, the individual cannot commit to the safety of themselves and others.

(8.8.2) Restraint and seclusion have no therapeutic value. They should never be used to "educate patients about socially acceptable behavior;" for purposes of punishment, discipline, retaliation, coercion, and convenience; or to prevent the disruption of the therapeutic milieu.

(8.8.3) Restraints shall be used only on the order of a physician with competency in psychiatry or a licensed independent practitioner recognized by state law. These professionals must be competent in providing alternatives to restraint, eliminating circumstances which give rise to the possible need for restraint, and applying restraints in safe and appropriate use. Restraints shall only be used for emergency safety use. Within an hour of initiating restraint, the physician or licensed independent practitioner shall complete a face-to-face evaluation of the patient. While in restraint the patient shall be continually and directly observed, person-to-person, by an appropriately trained professional. Specific behavioral criteria written by the physician, including the patient's verbal assurance of safety, shall specify when the restraints will be discontinued, to ensure minimum usage.

(8.8.4) Every restraint shall generate an incident analysis. An incident analysis is a process of identifying the basic or causal factors that underlie variation in performance, including occurrence or possible occurrence of a reportable event. The incident analysis shall be available to the designated legal entity within the state which will investigate reportable deaths and serious injury. Any death or serious physical injury associated with the use of restraint shall be reported to a designated legal entity within the state for investigation.

(8.8.5) The family, client, and involved staff should undergo a debriefing after each restraint or seclusion incident, within 24 hours. The circumstances leading to the restraint or seclusion and a discussion of why alternatives to restraint or seclusion failed should be documented in the clinical record. Future suggested interventions should be discussed at these debriefings. Following each use of restraint and seclusion, the patient should receive counseling specific to the incident.

(8.8.6) Treating professionals must adhere to the patient's advance directive, if there is one.

(8.8.7) Medication is typically important for the treatment of the symptoms of mental illness. However, medication should never be used for the purposes of discipline, staff convenience, immobilization, or reducing the ability to ambulate.

(8.8.8) Any institution using seclusion, restraint, time-out, or brief physical holds must provide appropriate initial and recurrent training of staff, not only in the safe application of these interventions, but also in techniques of de-escalation which reduce the need for these interventions. No staff member

should be involved in seclusion or restraint before completing the required training.

(8.8.9) When treating children and adolescents with mental illnesses, facilities and governing policies should differentiate between seclusion, inclusionary time-outs, and exclusionary time-outs.

(8.8.9.1) Seclusion is the involuntary placement of a child or adolescent, for any period of time, in a locked room where the child or adolescent is alone and is physically prevented from leaving.

(8.8.9.2) Inclusionary time-out is an involuntary procedure where a child or adolescent is separated from his/her peers in the presence of his/her peers.

(8.8.9.3) Exclusionary time-out is an involuntary procedure where a child or adolescent is separated in a designated area away from his/her peers but is not physically prevented from leaving.

(8.8.10) If children and adolescents are to be secluded, the order must be by a physician or a licensed independent mental health practitioner competent in these procedures and recognized by state law.

(8.8.11) While in seclusion and/or restraint, the child or adolescent should be constantly, visually monitored by staff. Video monitoring, if used by itself, is not sufficient.

(8.8.12) When treating children and adolescents with mental illnesses, mechanical restraint, brief physical holding, and "therapeutic holding" should be differentiated.

(8.8.13) Mechanical restraint should be generally avoided and used only in rare circumstances to protect the child or adolescent from self-harm and harm to others in emergency situations.

(8.8.14) Brief physical holding is a form of temporary physical restraint and is different than "therapeutic holding." "Therapeutic holding" is not supported by adequate scientific evidence or detailed practice guidelines, and, therefore, is not supported by NAMI as an accepted form of treatment.

(8.8.15) Brief physical holding should only be carried out by professionally recognized and trained mental health professionals licensed by a governmental body.

(8.8.16) Escorting and immediate physical separation of children and adolescents in conflict are not considered restraint.

8.9 Application of Less Lethal Weapons by Law Enforcement Officers

(8.9.1) The National Alliance on Mental Illness (NAMI) believes that the use of conducted energy devices (including stun guns, tasers, impact delivery systems, or any other similar non-firearm weapons)used by law enforcement officers responding to individuals with serious mental illness should be permitted only if the responding officer concludes that an immediate threat of death or serious injury exists, which cannot be contained by lesser means, and/or is likely to be hazardous to the officer(s), the individual, or a third party. Such devices should not be deployed when other means or methods of de-escalations are appropriate, available, and suitable for the crisis event, nor should these devices ever be used as a means of intimidation or inappropriate coercion.

(8.9.2) NAMI further believes that states should include, in statute, a requirement for the development and enforcement of standards and minimum training requirements for all law enforcement, corrections and other personnel who use or may potentially use these devices in the performance of their duties. This mandatory training must include information about effective methods of responding to people with mental illness in crisis with verbal and non-verbal crisis de-escalation techniques.

(8.9.3) States should also strictly define in statute categories of professionals who are authorized to use these devices in the performance of their duties and should strictly prohibit usage of these devices by those not identified as authorized users in statute.

(8.9.4) NAMI calls upon the states and the federal government to fund and promote research that documents the incidence of use of these devices and investigates both the short term and long term physical and psychological impact on people who have experienced the application of such devices. This research also should determine the potential dangers associated with risk factors, including but not limited to age and pre-existing medical conditions.

(8.9.5) Each use of these devices should be investigated by the respective law enforcement agency or institution in the same way that use of a firearm would be investigated by a law enforcement agency.

9. Legal Issues

9.1 Right to Treatment

(9.1.1) NAMI believes that every person with a serious mental illness is entitled to the same level of service afforded other physical illnesses. Every person is also entitled to be fully informed about specific medications and procedures and the risks, possible undesirable side effects of such medications and procedures, and other options. The risks and possible undesirable side effects of refusing treatment and what the alternatives are should also be a part of this information process. Every consumer has a right to be part of individual treatment planning. Every consumer has the right to be informed of all community services and supports.

(9.1.2) With adequate professional consultation, every person with a serious mental illness who has the capacity and competence to do so should be entitled to manage his or her own treatment. When an individual lacks capacity and competence because of his or her serious mental illness, however, the substitute judgment of others--subject to sufficient safeguards with frequent review--may be justified in determining treatment and possible hospitalization.

9.2 Involuntary Commitment/Court-ordered Treatment

(9.2.1) NAMI believes that all people should have the right to make their own decisions about medical treatment. However, NAMI is aware that there are individuals with serious mental illnesses such as schizophrenia and bipolar disorder who, at times, due to their illness, lack insight or good judgment about their need for medical treatment. NAMI is also aware that, in many states, laws and policies governing involuntary commitment and/or court-ordered treatment are inadequate.

(9.2.2) NAMI, therefore, believes that:

(9.2.3) The availability of effective, comprehensive, community-based systems of care for persons suffering from serious mental illnesses will diminish the need for involuntary commitment and/or court-ordered treatment.

(9.2.4) Methods for facilitating communications about treatment preferences among individuals with serious mental illnesses, family members, and treatment providers should be adopted and promoted in all states.

(9.2.5) Involuntary commitment and court-ordered treatment decisions must be made expeditiously and simultaneously in a single hearing so that individuals can receive treatment in a timely manner. The role of courts should be limited to review to ensure that procedures used in making these determinations comply with individual rights and due-process requirements. The role of the court does not include making medical decisions.

(9.2.6) Involuntary inpatient and outpatient commitment and court-ordered treatment should be used as a last resort and only when it is believed to be in the best interests of the individual.

(9.2.7) States should adopt broader, more flexible standards that would provide for involuntary commitment and/or court ordered treatment when an individual, due to mental illness

(9.2.7.1) is gravely disabled, which means that the person is substantially unable, to provide for any of his or her basic needs, such as food, clothing, shelter, health or safety; or

(9.2.7.2) is likely to substantially deteriorate if not provided with timely treatment; or

(9.2.7.3) lacks capacity, which means that, as a result of the serious mental illness, the person is unable to fully understand–or lacks judgment to make an informed decision about–his or her need for treatment, care, or supervision.

(9.2.8) Current interpretations of laws that require proof of dangerousness often produce unsatisfactory outcomes because individuals are allowed to deteriorate needlessly before involuntary commitment and/or court-ordered treatment can be instituted. When the "dangerousness standard" is used, it must be interpreted more broadly than "imminently" and/or "provably" dangerous.

(9.2.9) State laws should also allow for consideration of past history in making determinations about involuntary commitment and/or court-ordered

treatment because past history is often a reliable way to anticipate the future course of illness.

(9.2.10) An independent administrative and/or judicial review must be guaranteed in all involuntary commitment and/or court-ordered treatment determinations. Individuals must be afforded access to appropriate representation knowledgeable about serious mental illnesses and provided opportunities to submit evidence in opposition to involuntary commitment and/or court-ordered treatment.

(9.2.11) Responsibility for determining court-ordered treatment should always be vested with medical professionals who—in conjunction with the individual, family, and other interested parties—must develop a plan for treatment.

(9.2.12) The legal standard for states to meet to justify emergency commitments for an initial 24 to 72 hours should be "information and belief." For involuntary commitments beyond the initial period, the standard should be "clear and convincing evidence." Involuntary commitments and/or court-ordered treatment must be periodically subject to administrative or judicial review to ascertain whether circumstances justify the continuation of these orders.

(9.2.13) Court-ordered outpatient treatment should be considered as a less restrictive, more beneficial, and less costly treatment alternative to involuntary inpatient treatment.

(9.2.14) Efforts must be undertaken to better educate justice systems and law enforcement professionals about the relationship between serious mental illnesses and the application of involuntary inpatient and outpatient commitment and court-ordered treatment.

(9.2.15) Private and public health insurance and managed care plans must cover the costs of involuntary inpatient and outpatient commitment and/or court-ordered treatment.

9.3 Advance Directives and Healthcare Proxies

NAMI supports the efforts of states to develop processes by which caregivers and service providers work collaboratively with persons with serious mental illnesses to develop plans for treatment, services, and supports that are followed, when, and if, needed in the future.

9.4 Security of Trust Funds

NAMI believes that the assets of trusts established for the benefit of persons with serious mental illnesses should be secure from capture for any purposes other than those prescribed in the documents establishing the trusts.

9.5 Confidentiality

(9.5.1) NAMI acknowledges the dramatically changed environment of data linkages, data integration and initial inability to control access or identify recipients once data has been communicated without prior approval.

With the advent of electronic medical record systems, NAMI supports having safeguards for patient confidentiality to prevent inappropriate access to psychiatric information and drug and alcohol information.

(9.5.2) NAMI supports the involvement of consumer and family members as partners in the development of policy and use of data for decision making and the collaborative use of information by all stakeholders.

(9.5.3) NAMI supports the key roles of mental health professionals and practioners and their responsibilities, as part of good professional practice and professional ethics, to share information with both their patients or clients and family members and other verified caregivers.

(9.5.4) NAMI believes that national standards should be adopted for maintaining the privacy and confidentiality of individually identifiable medical records. These standards should serve as a floor, not a ceiling, for health privacy protections, and should apply to all entities, private and public, governmental and non-governmental which access health care records for any reason. States should be encouraged to add specific protections not provided under Federal law.

(9.5.5) NAMI believes that consumers (patients) of healthcare services own their own health records, especially those parts including any individual identifying information, while providers and managed care organizations are custodians of these records. Consumers have the right to inspect and amend their own healthcare records. Providers and managed care organizations should be allowed the use of aggregate data for purposes of quality assurance, and research.

(9.5.6) Federal legislation should require that consumers/patients provide informed consent for any use or disclosure of individually identifiable

health information which pertains to them. Lack of initial informed consent should not exempt providers and managed care organizations from providing emergency care, urgent care or medically necessary care to persons suffering from mental illnesses.

(9.5.7) Federal legislation protecting privacy and confidentiality of individually identifiable health information should contain strong and effective remedies for violations of these protections.

(9.5.8) NAMI believes that treatment providers are responsible for making known to caring families and caregivers any information necessary to the ongoing care of persons with serious mental illnesses. Professionals are obliged to accept information from family members or others who function in a caregiving role. In the event a patient objects to disclosure, the provider should use best clinical judgment in determining how to proceed.

(9.5.9) NAMI believes that law enforcement authorities must obtain search warrants or comparable determinations of probable cause by judges or magistrates before they can access individually identifiable medical information.

(9.5.10) Federal and state legislation should be drawn so as to protect individual privacy rights to the maximum extent feasible, while not impeding the conduct of biomedical, clinical or pharmaco-epidemiological research or treatment.

(9.5.11) When one physician makes a formal referral to another physician, clinical information, including information about medications, shall be made available to enhance clinical outcomes and avoid adverse treatment outcomes. When there is no formal referral, it is the responsibility of each treating professional to obtain information necessary to assure the provision of appropriate care and treatment.
In all cases, the exchange of such information shall be treated confidentially and protected. The sharing of clinical information or refusal to consent to sharing of clinical information shall not be used to deny treatment, adversely affect services, or otherwise discriminate against persons with severe mental illnesses.

(9.5.12) NAMI calls upon medical and mental health providers to implement electronic health information systems for the purposes of improving quality of care and of better facilitating the effective coordination and exchange of health and mental health information. These systems should be implemented in a way that assure the privacy and confidentiality of

protected health information, in accordance with applicable federal and state laws. NAMI calls for Federal studies on the feasibility of linking such systems to housing, employment and other supportive services to ensure continuity of care and coordination of services.

9.6 The Americans with Disabilities Act (ADA)

NAMI believes that a serious mental illness by itself does not constitute sufficient reason to deprive a person of the right to a free and appropriate education, the right to vote, or any other civil liberty. NAMI supports full and rapid implementation of the Americans with Disabilities Act (ADA) and enforcement of its statutory protection against discrimination in education, employment, public accommodation, and other life endeavors.

9.7 Education at all levels of Judicial and Legal Systems

NAMI believes that education about serious mental illness at all levels of judicial and legal systems is crucial to the appropriate disposition of civil and criminal cases involving individuals living with serious mental illness. Judges, lawyers, other court personnel, police officers, correctional officers, parole and probation officers, other law enforcement personnel, and emergency medical transport and service personnel should be required to complete a minimum of 20 hours of training about serious mental illness. Individuals living with serious mental illness and family members should be a part of this educational process and training should be consistent with available model standards for crisis intervention training.

9.8 Solitary Confinement

Solitary confinement is the placement of individuals in locked, highly restrictive and isolated cells or similar areas of confinement for substantial periods of time with limited or no human contact and few, if any, rehabilitative services. Placement in solitary confinement frequently lasts for weeks, months or even years at a time.

It is extensively documented that solitary confinement is used disproportionately in correctional settings for juveniles and adults with severe psychiatric symptoms. In some states, it is reported that more than half of all inmates in facilities utilizing the most extreme forms of solitary confinement and social isolation are diagnosed with serious mental illnesses. Solitary confinement for juveniles and adults living with serious mental illnesses serves no appropriate

purpose in terms of discipline, protection of the individual or others, or the individual's overall functioning in general prison settings and ability to follow prison rules. Instead, solitary confinement of persons with mental illnesses causes extreme suffering, has adverse long-term consequences for cognitive and adaptive functioning, disrupts treatment and exacerbates illness.

The damaging effects of solitary confinement may be even more severe for juveniles with mental illnesses. The impact of extreme isolation on youth whose brains are still developing can be permanent. Studies show that the placement of juveniles in solitary confinement significantly increases the risk of suicide and other self-injurious behaviors.

NAMI opposes the use of solitary confinement and equivalent forms of extended administrative segregation for persons with mental illnesses.

NAMI calls upon federal, state and other correctional authorities to provide mental health care alternatives to solitary confinement that include enhanced mental health treatment, services and programs, crisis intervention training for correctional officers and mental health step-down units. States that have adopted such proactive efforts to eliminate solitary confinement have documented highly positive results that include reduced psychiatric symptoms, less violence, and significant cost savings.

NAMI further calls upon federal, state and other correctional authorities to assure continued mental health treatment, including adherence to an individual treatment plan and access to qualified mental health care professionals, in conditions of short-term disciplinary or administrative segregation.

10. Criminal Justice and Forensic Issues

10.1 Ultimate Responsibility of Mental Health Systems

Mental health systems have ultimate responsibility for treating all people with severe mental illness. A substantial number of people with severe mental illness require twenty-four hour, seven days per week structured care, either for long or short periods of time. It is never appropriate to allow the care of such persons to be shifted to the criminal justice system.

10.2 Therapeutic Jurisprudence

NAMI endorses the principal of therapeutic jurisprudence, which emphasizes that the law should be used, whenever possible, to promote the mental and physical well being of the people it affects. For example, in a system

characterized by therapeutic jurisprudence, people with serious mental illnesses charged with non-violent crimes are diverted into programs designed to address their treatment and service needs, rather than incarcerated. Individuals with serious mental illnesses convicted of serious crimes are provided with humane and appropriate treatment while incarcerated. And, these individuals are provided with appropriate linkages to needed services and supports upon discharge to enable them to successfully reenter their communities.

10.3 Collaboration

NAMI believes that state and local mental health authorities must work closely in conjunction with state and local correctional and law enforcement agencies to develop strategies and programs for compassionate intervention by law enforcement, jail diversion, treatment of individuals with serious mental illnesses who are incarcerated, and discharge planning and community reintegration services for individuals with serious mental illnesses released from correctional facilities.

(10.3.1) NAMI believes that at least 25% of law enforcement first responders in each jurisdiction should be trained for a minimum of 40 hours consistent with model standards for police crisis intervention training in order to better assure safety, appropriate de-escalation, less lethal consequences and opportunities for treatment.

10.4 Boot Camps

Youth with serious mental illnesses should never be placed in boot camps, “scared straight” or similar programs that use punishment as the primary source of behavior change. There is sufficient evidence that these programs are non-therapeutic and cause harm. In some cases, placement in boot camps has led to the unnecessary and tragic deaths of these youths.

10.5 Right to Treatment (Regardless of Criminal Status)

(10.5.1) Humane and effective treatment for serious mental illnesses while in correctional settings is the constitutional right of inmates with severe mental illnesses. NAMI strongly urges the enactment of state statutes expanding treatment programs within prison and jail settings, including first line access to new generation medications whenever clinically indicated.

(10.5.2) NAMI endorses state laws and policies establishing systems of community treatment for offenders with serious mental illnesses who are released on parole and/or are in the community on probation or parole status.

10.6 Jail Diversion

(10.6.1) NAMI believes that persons who have committed offenses due to states of mind or behavior caused by a serious mental illness do not belong in penal or correctional institutions. Such persons require treatment, not punishment. A prison or jail is never an optimal therapeutic setting.

(10.6.2) NAMI supports a variety of approaches to diverting individuals from unnecessary incarceration into appropriate treatment, including pre-booking (police-based) diversion, post-booking (court-based) diversion, alternative sentencing programs, and post-adjudication diversion (conditional release).

10.7 Violence

(10.7.1) NAMI recognizes that when dangerous or violent acts are committed by persons with serious mental illnesses, it is too often the result of neglect or ineffective treatment. Mental health authorities must implement and sustain policies, practices and programs that provide access to early diagnosis, crisis intervention, appropriate treatment (including integrated treatment when there is co-occurring substance abuse) and support that saves lives. NAMI strongly advocates that people with mental illnesses not be stigmatized and subjected to discrimination by being labeled “criminal” or “violent.” There is very rarely correlation between mental illness and violent behavior and mental illness must not be confused with sociopathic behavior.

(10.7.2) NAMI recognizes that epidemic gun violence is a public health crisis that extenuates risks of lethal harm by others, self-harm and harm to others for people with mental illnesses. Gun violence is overwhelmingly committed by people without mental illness. NAMI believes that firearms and ammunition should not be easier to obtain than mental health care. NAMI supports reasonable, effective, consistently and fairly applied firearms regulation and safety as well as widespread availability of mental health crisis intervention, assistance and appropriate treatment. In the absence of demonstrated risk, people should not be treated differently with respect to firearms regulation because of their lived experience with mental illness.

10.8 Death Penalty

NAMI opposes the death penalty for persons with serious mental illnesses.

(10.8.1) NAMI urges jurisdictions that impose capital punishment not to execute persons with mental disabilities under the following circumstances:

(10.8.1.1) Defendants shall not be sentenced to death or executed if they have a persistent mental disability, with onset before the offense, characterized by significant limitations in both intellectual functioning and adaptive behavior as expressed in their conceptual, social, and practical adaptive skills.

(10.8.1.2) Defendants shall not be sentenced to death or executed if, at the time of their offense, they had a severe mental disorder or disability that significantly impaired their capacity (a) to appreciate the nature, consequences or wrongfulness of their conduct, (b) to exercise rational judgment in relation to conduct, or (c) to conform their conduct to the requirements of the law. A disorder manifested primarily by repeated criminal conduct or attributable solely to the acute effects of alcohol or other drugs does not, standing alone, constitute a mental disorder or disability, for purposes of this provision.

(10.8.1.3) Sentences of death shall be reduced to lesser punishment if prisoners under such sentences are found at any time subsequent to sentencing to have a mental disorder or disability that significantly impairs their ability (a) to understand and appreciate the nature of the punishment or its purpose, (b) to understand and communicate information relating the death sentence and any proceedings brought to set it aside, or (c) to make rational choices about such proceedings.

10.9 Insanity Defense

NAMI supports the retention of the "insanity defense" and favors the two-prong ("ALI")[1] test that includes the volitional as well as the cognitive standard.

[1] *The "ALI test" refers to the rule for insanity adopted in Section 4.01(1) of the American Law Institute'' Model Penal Code. The Code states that "a person is not responsible for criminal conduct if at the time of such*

NAMI advocates for research and services in response to major illnesses that affect the brain, including schizophrenia, schizoaffective disorder, bipolar disorder, major depressive disorder, obsessive-compulsive disorder, panic and other severe anxiety disorders, borderline personality disorder, post traumatic stress disorder (PTSD), autism and pervasive developmental disorders, and attention deficit/hyperactivity disorder.

(10.9.1) **"Guilty but Mentally Ill"**

NAMI opposes "guilty but mentally ill" statutes as presently applied because they are used to punish rather than to treat persons with serious mental illnesses who have committed crimes as a consequence of their serious mental illnesses.

(10.9.2) **"Guilty except for insanity" and other alternative terminology for the insanity defense**

NAMI supports systems that provide comprehensive, long-term care and supervision to individuals who are found "not guilty by reason of insanity", "guilty except for insanity", and any other similar terminology used in state statutes[2].

(10.10.3) **"Informing Juries about the Consequences of Insanity Verdicts"**

NAMI Believes that juries in cases where the insanity defense is at issue should be informed about the likely consequences of an insanity verdict to enable them to make a fair decision.

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conduct as a result of mental disease or defect he lacks substantial capacity either to appreciate the criminality (or alternatively, wrongfulness) of his conduct (cognitive standard) or to conform his conduct to the requirements of law (volitional standard)."

[2] *States currently apply three different terms to verdicts incorporating a formal finding or acknowledgement of mental illness.*
"Not guilty by reason of insanity" is the traditional term used when a person is determined as not criminally responsible due to mental illness. Individuals found "not guilty by reason of insanity" are typically sentenced to secure psychiatric treatment facilities instead of prison.
"Guilty but mentally ill" (GBMI) statutes have been adopted in the criminal codes of a number of states. These statutes currently function very similarly to "guilty" verdicts. An individual found GBMI could be sentenced to life in prison or even to death. Additionally, a verdict of GBMI does not guarantee psychiatric treatment.
"Guilty except for insanity" statutes have been adopted in several states such as Oregon and Arizona as substitutes for "not guilty by reason of insanity." These states have developed effective systems for providing long-term treatment and supervision to individuals who are found "guilty except for insanity."

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