

**PUBLIC
POLICY
PLATFORM**

of

The National Alliance on Mental Illness
NAMI California

By the Board of Directors
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Acknowledgements

The NAMI California Board Members of the Policy Committee and the NAMI California Chief Executive Officer wish to thank the many local Affiliates and state organizations for their contributions to this policy compilation. We particularly wish to acknowledge the valuable contributions of the members of the NAMI California Board of Directors, past and present.

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

NAMI California

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Language

NAMI California's policy is to acknowledge that severe and persistent mental illnesses are illnesses that affect the brain. Therefore, throughout this document, the term "brain disorder(s)" is used interchangeably with "severe and persistent mental illness(es)."

NAMI California 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. (Revised March 2006)

NAMI California requires that all NAMI California documents and NAMI California 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 California condemns all acts of stigma directed against persons with serious 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 California considers acts of stigma to be discrimination.

NAMI California believes, in accordance with current scientific evidence, that persons who are receiving appropriate treatment and services for a serious mental illness are no more violent than the population at large. NAMI California 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 California especially deplores the exploitation of people with serious mental illnesses by journalists, advertisers, advertising agencies, the entertainment industry, and others for commercial gain or other advantage.

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1. Identity and Mission

1.1 Identity. NAMI California is a grassroots organization of individuals with serious mental illnesses and their family members whose mission is to eradicate serious mental illnesses and improve the quality of life of persons of all ages who are affected by them.

1.2 Primary Functions. The primary functions of NAMI California are support, education, and advocacy for consumers and their families; for research and services; and for 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 consumers when it is necessary to make the distinction.

1.3 Scientific Approach. NAMI California 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 and manageable 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 Supportive Growth. NAMI California's roots grew from the need of people for knowledge, understanding, sharing of grief, relief of guilt, mutual support, and mutual love. Increase in NAMI California's membership is likely to be concentrated in families and consumers needing and seeking these same needs. Family means consumers and their parents, siblings, adult children, spouses, and other involved relatives.

1.5 Peer Support. While primary peer support is concentrated in local Affiliates and conventions, all components of NAMI California declare:

(1.5.1) Statement 1. Together we can give each other strong support;

(1.5.2) Statement 2. The illness is treatable;

(1.5.3) Statement 3. It's not anyone's fault;

(1.5.4) Statement 4. You don't need to explain anything - we already know;

(1.5.5) Statement 5. You can survive as an intact family;

(1.5.6) Statement 6. With dedication and unity, we have enormous strength through which we can accomplish constructive change.

1.6 Mission. Persons with serious mental illnesses share many similar problems with persons with other disorders and disabilities. To achieve our own goals, NAMI California 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 California maintains the right to forcefully advocate for the rights of persons with serious mental illnesses, even when our views conflict with the views of other disability groups. NAMI California places the highest priority on medical treatment, services,

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education, and rehabilitation 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 California identifies as the priority population those persons of all ages who have severe and persistent mental illnesses, including:
(Revised March 2006)

(2.1.1) Disorders. 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. These disorders represent the major mental disorders that current scientific data and consensus conclude are identifiable, disabling medical illnesses, with significant biological underpinnings, and requiring treatment. (Revised March 2006)

(2.1.2) Severity. Other severe and persistent mental illnesses that affect the brain:

(2.1.3) Risk. with seriously disabling consequences or a high risk of mortality;

(2.1.4) Term. that have a long-term course.

2.2 Additional Support. NAMI California believes that individuals with these 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 wellness.

2.3 Cultural Diversity.

(2.3.1) Non-English Access. Persons of cultural, racial, religious, and ethnic diversity and those for whom English is not the primary language have unique characteristics that sometimes impede their abilities to benefit fully from existing treatment, training, and rehabilitation programs. These differences must be respected and afforded appropriate representation must be strived for, both within the governance of the services sector and within NAMI California.

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

(2.3.3) Non-Bias. NAMI California urges the incorporation of ethnic and cultural perspectives and competence into the design and implementation of programs and procedures for persons with serious 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) Provider Diversity. NAMI California believes that providers must have training and sensitivity to cultural diversity.

(2.3.5) No Tolerance. NAMI California 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. NAMI California calls for the development of suitable, non-discriminatory community residences and the same improved services for elderly persons with serious mental illnesses as for other adults.

2.5 Adults Who Are Veterans.

(2.5.1) Services. NAMI California believes that veterans should receive the same full range of integrated services within the hospital and upon discharge to the community that are received by other people with serious mental illnesses.

(2.5.2) Programs and Treatment. NAMI California calls for veteran's hospitals and veteran's outpatient treatment programs to be held to the same standards of performance as all other hospitals and outpatient treatment programs.

2.6 Persons Who Are Homeless and/or Missing

(2.6.1) Treatment. NAMI California 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 California 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) Decency. NAMI California 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) Families. When helping to reunite families, NAMI California 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) Jail. NAMI California deplores the commonplace use of jails and prisons to warehouse persons with serious mental illnesses who are homeless.

2.7 Persons Infected with the HIV Virus

(2.7.1) Treatment. NAMI California 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 with persons that are part of their support network.

(2.7.2) Testing. Persons with serious mental illnesses living in institutional settings have been identified as high risks for HIV infection. Therefore, NAMI California 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) Resources. NAMI California 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.

- (2.7.4) Organization Collaboration.** NAMI California will work with organizations that serve people who test, or are at risk of testing, HIV-positive to improve services for people with co-occurring mental illnesses and provide education and support for their families and friends.

2.8 Children with Serious Mental Illnesses

- (2.8.1) Environment.** NAMI California 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) Timing.** NAMI California 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) Treatment location.** NAMI California 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) Parents and Caregivers.** NAMI California 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) Educational Administrators.** NAMI California 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) Government Officials.** NAMI California 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) Integration.** NAMI California 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.

- (2.8.8) Detainment.** 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) Crisis Management. 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) Educational Crisis Management. 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) De-Escalation. 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) Coercion. NAMI California believes that families should never be coerced to relinquish custody of their dependent children with serious mental illnesses in order to obtain care, treatment, or 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) Families. NAMI California recognizes the critical role that families play in the recovery and development of their children. Therefore NAMI California 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) Government Leaders. NAMI California 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) Primary Care Providers. NAMI California 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.

(2.8.16) Intervention Measures. As knowledge about effective prevention and early intervention measures increases, NAMI California urges their implementation and will work to spread awareness in order to prevent or reduce full-blown symptoms and to reduce dysfunction caused by symptoms.

2.9 Minor Children of Parents with Serious Mental Illnesses. NAMI California 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.

2.10 Child Custody and Family Unity. NAMI California believes that no child should be separated from a parent solely on the basis of either the parent's or the child's serious mental illness. Family support can be integral to recovery, and mental illness should not be equated with violence or dangerousness.

(2.10.1) Family. Every family should have access to treatment and support services that meet their unique needs.

(2.10.2) Custody. A parent or parents should never have to relinquish custody of a child with a serious mental illness in order for that child to receive adequate treatment and services. Crisis stabilization, crisis residential, and other treatment options should be available for children in all communities, and should integrate family support. A parent with serious mental illness should not be presumed unable to care for a child or children solely on the basis of his or her diagnosis of mental illness. Instead, wraparound services should be provided, including mental health services and social services.

(2.10.3) Reunification. Parents with serious mental illness in dependency proceedings must be eligible for reunification services, and the court system should provide specialized services to families affected by serious mental illness.

(2.10.4) Child Protective Services. Child Protective Services workers should be trained to recognize the signs and symptoms of serious mental illness, and to employ appropriate strategies with families affected by serious mental illness.

(2.10.5) Visitation. Parents who are being treated for mental illness in an in-patient setting must be provided with visitation opportunities with their children, if desired, in order to preserve the parent-child relationship. In-patient treatment should also offer parenting services and services for children impacted by serious mental illness in their family.

3. Treatment

3.1 Access to Treatment

(3.1.1) Timeliness. NAMI California believes that individuals with mental illnesses must have timely access to treatments that have been recognized as effective by

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the Food and Drug Administration (FDA) and the National Institute of Mental Health (NIMH). NAMI California is adamant that individuals with mental illness have timely access to clinically appropriate medications, evidence-based services, and treatment, including psychotherapy, that are provided a person-centered approach.

(3.1.2) Limitations. NAMI California 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.

(3.1.3) Medication. 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.

(3.1.4) Psychotherapy. 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.

(3.1.5) Providers. 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) Safeguards. Early diagnosis and early initiation of treatment are both medically 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 older adults.

(3.2.2) Children and Adolescents. In particular, NAMI California urges full use of the Early Periodic Screening Diagnostic Tool (EPSDT) for children. Treatment plans for children and adolescents must be reviewed every three months.

3.3 Mental Health Screening

(3.3.1) History. NAMI California 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) Affirmation Steps. 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:**

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

(3.3.2.2)Consent. Parental consent or consent from legally authorized surrogates must be obtained for all mental health screenings.

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

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

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

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

(3.3.2.7)Studies. 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.

(3.3.2.8)Schools. 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.

(3.3.2.9)Mental Health Evaluation. 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.

(3.3.2.10)Treatment Access. 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.

(3.3.2.11)National Effort. 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) Definition. 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, recovery or wellness services, and community support services. Treatment for persons with serious mental illnesses, who have other disorders or disabilities, including substance abuse (dual diagnosis), should encompass a wide array of options. Options should be determined by the client in conjunction with family members and those significantly involved with treatment and service provision.

- (3.4.2) Needs and Services.** A treatment plan should include whatever can be made available to aid in the individual recovery of the consumer reflecting assessed needs and may include a range of available services. Criteria for determining the treatment plan should include assessment of behaviors resulting from changes in environment as well as the skills development and social supports needed to respond to these changes.

3.5 Outpatient Treatment

- (3.5.1) Accessibility.** Outpatient treatment must be readily accessible to the individual in his or her own community. Ideal treatment should meet the needs of the consumer and can include new-generation medications, symptom therapy, supportive psychotherapy, Assertive Community Treatment (ACT), recovery/wellness and peer support.
- (3.5.2) Emergency Services.** Easily accessible emergency services are available 24 hours a day, seven days a week. Emergency services should not have to be accessed through the criminal justice system. If a person is in a psychotic state 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.
- (3.5.3) Hospitalization.** Partial-hospitalization should be used selectively with monitoring to ensure that the stay is goal-oriented.
- (3.5.4) Community Systems.** Community systems must be comprehensive, person-centered, and integrated, and should include medical, dental, and personal-care services as well as daily-living skills, supported housing, education, and pre-vocational and vocational training.

3.6 Inpatient Treatment

- (3.6.1) Services.** Inpatient services ranging from short-term acute care or respite care to long-term care must be available and accessible. Linkages between inpatient and outpatient treatment and community support systems must be in place to ensure continuity of care.
- (3.6.2) Hospitalization.** Short-term and longer-term hospitalization must be provided as determined to be necessary by the ITP.
- (3.6.3) Long-Term Care.** Long-term care, such as IMDs, must be available for those in need.

3.7 Family Involvement in Treatment

- (3.7.1) Treatment.** NAMI California believes that treatment should be collaborative. 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 or maintain serious mental illnesses, their knowledge of and relationship with the consumer is unique and can be a significant help in determining the best course of treatment.

- (3.7.2) Substitution.** 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.
- (3.7.3) Participation.** Treatment should be client- and family-centered. 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) Common Courtesy.** Common courtesy dictates that consumers and family members 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 its treatment.
- (3.7.5) Advocacy.** Family and consumer advocacy should always be encouraged. In circumstances where the mental health system is understaffed, under-financed, and services are uncoordinated, or other problems impede proper service delivery, family and consumer advocacy is effective and powerful.
- (3.7.6) Stigma.** 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 don't care or are not concerned. 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 patient and the treatment system changes.
- (3.7.7) Request for No Family Involvement.** 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. A one-time rejection of family involvement should not prevent ongoing requests for authorization of family participation.
- (3.7.8) Children.** All treatment and services provided to children living with serious mental illnesses and 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, skills, and support to make informed decisions as equal partners in the treatment planning and delivery processes. Children living with mental illnesses should be included in all aspects of treatment planning whenever possible.

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;

(3.7.9) Child-Serving Systems. 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 California believes that community-based services must include regular measurements of consumer and family satisfaction and dissatisfaction with these services. These measurements are often 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 California does not endorse any specific treatment or service for mental illnesses. NAMI California does advocate for general models of service such as evidence-based programs, clinical practices, and FDA-approved treatments.

3.10 Access to Psychiatric Medications.

(3.10.1) Accessibility, Federal. NAMI California supports the following integrated and comprehensive federal strategies to ensure open access to psychiatric medications in the current budget deficit environment.

(3.10.1.1) Increase. Increase the Federal Medical Assistance Percentage (FMAP) for people with serious mental illnesses;

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

(3.10.2) Accessibility, State. NAMI California 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; All formularies used by counties’ mental health departments and other service providers should focus on efficacy.

3.11 Prescription Privileges for Psychologists, Workforce Shortages

NAMI California does not endorse proposals currently before state legislatures to expand prescribing privileges to psychologists. NAMI California 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 California 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 underserved regions of the country.

3.12 Cultural Competence

(3.12.1) Definition. 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) Definition of Culture. 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, 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. 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) Accessibility of Services.** 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) Limited English Proficiency.** 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) Compliance.** 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) Compliance Enforcement.** 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) Funding Opportunities.** 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) Education and Awareness. NAMI California 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) Mental Health Workforce. NAMI California 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 culturally competent skills of the nation's existing mental health service delivery providers.

3.13 Wellness

(3.13.1) Validation of Wellness. People living with serious mental illnesses are at increased risk for other serious medical illnesses such as diabetes, heart disease, cancer, and respiratory diseases. Recent research indicates that they also have a much shorter life span than other Americans. This disparity has increased over time and merits increased attention and funding for promoting wellness among individuals with serious mental illnesses.

(3.13.2) Promotion. Consumers, family members and providers should promote and encourage wellness. Wellness encompasses mind, body, and spirit. It can include nutrition, exercise, rest, dental care, physical exams, and tobacco, drug, and alcohol cessation.

(3.13.3) Recovery. Wellness is a part of the recovery process. Consumers must be empowered to achieve wellness through consumer education and peer support.

(3.13.4) Providers. Providers must make wellness a priority and provide access to relevant 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 monitoring by a nurse. Those who provide meals must ensure nutritious choices, including fresh fruits and vegetables.

(3.13.5) Dental Access. NAMI California 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.

(3.13.6) Integrated Healthcare. NAMI California also calls for better integration of physical and mental healthcare, including sharing relevant health indicators. Psychiatrists 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.

(3.13.7) Fiscal Incentives. 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.

(3.13.8) Benefits. 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

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 families.

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 California 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 Transition Age Services and Supports

NAMI California 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.

4.4 Educational Programs

(4.4.1) System of Care. NAMI California 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.

(4.4.2) Peer Support. 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.

4.5 Training and Qualifications for Providers

NAMI California 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.

4.6 Integrated Health and Mental Health Care

NAMI California 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 California 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.

4.7 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) Basis.** NAMI California believes that it is the responsibility of federal, state, and local governments to develop and maintain comprehensive community support systems of treatment and services for the priority population as well as short-and long-range plans for all those with serious mental illnesses.
- (5.1.2) Treatment.** NAMI California 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) Practices and Services.** NAMI California believes that all publicly-funded community service providers must offer recovery-oriented, evidence-based practices and services that customers need and can readily access. These must include the availability of new generation 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 and persistent mental illness, 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.

(5.1.3.1) Endorsement. NAMI California endorses integrated, rather than sequential or collaborative-parallel treatment programs for persons with co-occurring¹ mental illness and addictive disorders. (Revised March 2006)

(5.1.3.2) Staff. Because the majority of people with serious mental illnesses have a co-occurring substance abuse disorder, NAMI California believes that integrated mental health and substance abuse treatment must be delivered at the same treatment site using cross-trained staff.

5.2 Continuity of Care

Every person should have a single service manager or management team who keeps 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 the individual's treatment unless the consumer desires a change.

5.3 Housing

(5.3.1) Basis. Housing is critical to recovery and must be available to individuals with mental illness.

(5.3.2) Needs. Individuals with serious mental illnesses need a wide array of options for permanent, decent, and affordable housing, based on an individual's needs and choices. These options may include group homes and independent living in apartments or houses. NAMI California reinforces and encourages living in the community whenever that option is available and suitable to a consumer's needs and choices. Funding mechanisms should support consumer choice, and should follow the individual with respect to all housing choices, including housing provided by caregivers.

(5.3.3) Services. Housing options should offer appropriate supportive services, including but not limited to: case management; tenancy support; clinical services; employment training and education; transportation; and crisis intervention. Housing should also be monitored by the appropriate licensing and enforcement agencies for quality, including cleanliness and safety.

(5.3.4) Continuum of Care. Housing options must be provided across the continuum of care and include crisis residential facilities for adults and children. Additionally, hospitals and inpatient treatment facilities must ensure that all discharge plans include safe and secure housing. In no case should an individual with mental illness be discharged without a place to live.

(5.3.5) Loss of housing. No individual with a serious mental illness should lose his or her housing in the community during periods of inpatient treatment. Additionally, no individual should lose his or her ability to obtain housing assistance due to care provided by family members.

(5.3.6) Housing Funds. NAMI California recommends that an equitable portion of federal and state housing funds be designated for persons with serious mental illnesses and redirected to an integrated funding stream to finance the housing

¹ "dual-disorders" changed to "co-occurring" by friendly amendment in Board discussion 11/11/05

component of a unified system of treatment, services, and supports for persons with serious mental illnesses.

- (5.3.7) Opposition.** NAMI California opposes all housing statutes, regulations, and ordinances that discriminate by limiting fair and equal access for people with serious mental illnesses, such as special use permits, occupancy limitations, mandated dispersal of residences, or private restrictions included in covenants, deeds, or lease agreement. In addition, NAMI insists that persons with serious mental illnesses not be specifically singled out for living arrangements segregated from other populations in publicly-supported housing.
- (5.3.8) Cohabitation.** NAMI California believes that in those cases where the independent living arrangement is shared by two or more persons, it is preferable that the choice of "roommates" be left up to the residents. Providers and caregivers do not have the right to restrict such choices or determine compatibility based upon age, race, ethnic background, disability, religion, diagnosis, or other such criteria. In no cases should residents in independent living arrangements be expected to develop a custodial role unless they so choose.
- (5.3.9) Rights.** NAMI California affirms that consumers have the right to privacy, security, stability, and dignity in housing.
- (5.3.10) Familial Responsibility.** NAMI California believes that it is not the family's responsibility to provide housing for a family member who has a serious mental illness. For those willing to accept this responsibility, there must be adequate training and education about available benefits and options. No one with a mental illness should be housed in a nursing home or similar long-term care facility without an independent determination of a geriatric or other appropriate medical condition.

5.4 Rehabilitation, Employment, and Education

- (5.4.1) Right to Participate.** NAMI California believes that consumers have the right to participate in activities that are productive and meaningful to them and that they must be offered extensive training and rehabilitation to help them achieve their highest potential level of recovery and independence.
- (5.4.2) Service Plans.** Individual service plans must be flexible and open-ended and based on consumer preference, allowing for change as the consumer requests it or needs it.
- (5.4.3) Care Managers.** Care managers must be responsible for providing programs for consumers to learn or relearn daily living skills, appropriate grooming and attire, medication and money management, social, physical, and recreational activities, volunteer opportunities, and whatever else the individual service plan directs (i.e. nutritional planning, transportation consulting, vocational training, etc.). Additionally, persons may need assistance with the development and/or redevelopment of their social skills and ability to meaningfully interact with others. Rehabilitation counselors must fully inform consumers of all services that will assist with their personal goals and to provide smooth and timely access to these services, including aptitude testing, vocational skills, GED education courses, job coaching and job placement.

(5.4.4) Vocational Rehabilitation. NAMI California believes that state vocational rehabilitation agencies and state mental health agencies should develop cooperative agreements to ensure that long-term supports are available for people with serious mental illnesses who are in supported employment.

(5.4.5) Definition Refinement. NAMI California continues to advocate for a refinement of the definition of serious mental illnesses under the Individuals with Disabilities Education Act (IDEA) in order to improve the access to the design of appropriate individual programs to meet each person's unique education needs.

(5.4.6) Affirmative Action Endorsement. NAMI California endorses an affirmative-action policy for recruiting consumers as students in educational programs that will prepare them for careers in the delivery system that serves persons with serious mental illnesses. NAMI California encourages hiring such persons as service providers.

5.5 Consumer-Run Programs

NAMI California supports and encourages: 1) self-help activities; 2) consumer-run programs including peer support, housing, day centers, small businesses, clubhouses, and drop-in centers. NAMI California 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) Education Opportunity. NAMI California believes that a transformed recovery-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 providers.

(5.6.2) Peer Support. 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 government grants, and further system resources must be made available for peer educational programs to establish an evidence base comparable to the rigorous scientific studies conducted by fully-funded system-based programs.

5.7 Mental Health Services Act (MHSA)

NAMI California fully supports the MHSA as an effective and important part of the mental health system in California.

(5.7.1) Oversight. Although all funds for the MHSA are funded by county, it's important to have transparent, standardized statewide oversight with the ability to intervene in cases where monies are being misspent or ineffectively spent. Oversight and Accountability bodies must direct all funding toward the most effective and used programs to ensure the best outcomes for individuals and

(5.7.2) Outcome measurement. NAMI California recognizes the need to ensure programs are effective in serving families and individuals living with severe mental illness and those who are likely to develop severe mental illness. Funded programs should have the ability to produce outcomes which impact the reduction of severe mental illness or the early intervention in its development.

(5.7.3) Family and Consumer Driven. All programs that serve individuals and families with mental illness should be conceived and designed by those the programs purport to serve. Processes for family and consumer involvement should be uncomplicated and easy to access. This includes any attempt to reform the MHSA and/or any attempts to fund new services or supports from MHSA funding.

(5.7.4) Not to supplant funds. The MHSA was intended to augment the current mental illness prevention and care system and not to supplant it. NAMI California encourages policy makers to ensure systems of care are fully funded outside of the additional funds within the MHSA and not rely on the MHSA as a primary care “do it all” funding source. MHSA funds should not be used to fund programs outside of the intended purpose as stated in the act.

(5.7.5) Services to Individuals living with Serious Mental Illness (SMI) and their Families. MHSA funds must be directed toward those who are the most in need and their families. Services need to encompass the entire continuum of care; from low level interventions designed to help individuals in the early stages of SMI and their families. These can include programs like respite care and navigation services, to more complex and long-term care which could include increasing the number of available inpatient beds, co-occurring serious substance use treatment for those with dual diagnosis who have no other funding source, treatment for anosognosia, and supportive housing/employment.

5.8 Prevention and Early Intervention Services (PEI)

MHSA-funded early diagnosis and treatment for severe mental illness, including first psychotic episode.

(5.8.1) Early Intervention. Early Intervention is critical in preventing mental illness. NAMI California believes that all persons should have the opportunity for rapid diagnosis and treatment if they develop a severe mental illness. They should also be treated with dignity and respect during the period of time needed for diagnosis and treatment. This should also include support and services for family members and/or primary caregivers and their needs.

(5.8.2) PEI Programs. PEI Programs should serve to prevent and/or intervene early in serious mental illness. NAMI California urges all county mental health departments in California to start a program(s) with PEI funds to identify individuals who are developing early signs and symptoms of a severe mental illness or have their first full blown psychotic episode and immediately start treatment that is defined by the county’s community support and services full services partnership.

There should be a definite plan for transferring these individuals from the PEI program to the CSS full partnership program, so that these individuals do not lose services or be lost from the county services during the transfer. These programs should cover the age span of the county’s population, including children, transitional-aged youth, adults and older adults. These programs should also work in traditionally underserved or highly impacted areas where access to mental health services may not be as established.

(5.8.3) PEI Tools. NAMI Programs are valuable PEI Tools - NAMI California supports all local Affiliates’ quests in obtaining MHSA PEI funds from their

county mental health departments to enact programs for early diagnosis and treatment for symptoms and signs of mental illness including the first psychotic episode. Additionally for preventing subsequent psychotic episodes or the debilitation that may occur from ongoing or recurrent severe mental illness.

5.9 Categories and Admin Funds

NAMI California believes that the categories in the MHSA must reflect the needs and experiences of families in California. The current categories (WET, CSS, PEI, INN, and CF/TN) have been developed over time to attempt to meet those needs. While we don't believe we should be locked into preset categories to address evolving needs, any change to these categories must be led by the families and individuals the MHSA purports to serve.

6. Financing of Treatment and Services

6.1 Private-Sector Healthcare Reform

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

(6.1.2) Provisions. NAMI California supports the establishment of provisions to ensure equal access to affordable health care for every American. It is critical that coverage of serious mental illnesses be equal in scope and duration to coverage of other illnesses without lifetime maximum-benefit caps and without other limits more restrictive than those required for other disorders.

(6.1.3) Nondiscrimination. NAMI California urges passage of legislation to mandate nondiscriminatory coverage of serious mental illnesses with other physical diseases. Private-sector health plans must cover all proven-effective treatments appropriate to the needs of individuals with serious mental illnesses.

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

(6.1.5) Employee Retirement Income Security Act. NAMI California believes that the Employee Retirement Income Security Act (ERISA) of 1974 represents a significant obstacle to state government efforts to broaden access to services for those who have serious mental illnesses. NAMI supports efforts of states to gain waivers of ERISA and any Act on the Federal level to allow these waivers. These waivers would prohibit self-insured employers from avoiding compliance with state-mandated minimum-benefit laws.

(6.1.6) Healthcare Rationing. NAMI California opposes healthcare rationing.

6.2 The Role of the Public Sector

(6.2.1) Essential Needs. NAMI California 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. The essential needs of these individuals and the obligations of society must be addressed irrespective of decisions which are made concerning what level of government should have control over such functions, what proportions of the financing each level should take, and how much should be privatized.

- (6.2.2) Ageism.** Persons of all ages who suffer from serious mental illnesses are frequently unable to provide for themselves because of acute or chronic symptoms that result from their disorders. 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, medical insurance, other health and social services, shelter and housing, education, transportation assistance, legal assistance, advocacy, training, and employment assistance.

6.3 Medicaid, Medicare, and Veterans Benefits

(6.3.1) Medicare

- (6.3.1.1) Medication.** Medication prescribed for the treatment of serious mental illnesses must be fully covered under the Medicare Part D program.
- (6.3.1.2) Co-Payments.** Co-payments imposed on outpatient mental health services must be equalized with all other Medicare co-payments.
- (6.3.1.3) Lifetime Limit.** The existing 190-day lifetime limit on inpatient psychiatric hospitals must be eliminated. The existing partial hospitalization benefit should be re-examined and revised to include a continuum including intensive case management, psychiatric rehabilitation, and assertive community treatment.
- (6.3.2) Standards.** Standards of medical necessity for treatment of mental illness must be the same as for all other medical services.
- (6.3.2.1) Diagnosis.** All persons served must have a documented diagnosis.
- (6.3.2.2) Treatment Plan.** All persons served must have an individualized treatment plan with clinical goals and plans of action. Progress in implementing the plan must be documented.
- (6.3.2.3) Provider Validation.** Providers must be licensed, certified, or recognized by the state and meet national standards for clinical care.
- (6.3.3) Records.** Providers are obligated to clinically document medical necessity and accurately bill for services rendered. All records must document the medical necessity of the services rendered.
- (6.3.4) Social Security Disability Insurance.** Persons receiving Social Security Disability Insurance (SSDI) who seek work should be allowed to continue their Medicare insurance coverage for an indefinite period. Persons who go off Medicare because they have obtained employment should be automatically re-enrolled in Medicare if they subsequently have a clinical relapse.
- (6.3.5) Patient Protection.** Comprehensive patient protections should consistently be an integral part of all health benefit programs, including Medicare. [Refer to other sections of this Platform for specific protections]
- (6.3.6) Risk Adjustment.** Any risk adjustment payment mechanism adopted by Medicare must include both severity and chronicity of mental illness. (Revised February, 1999)

6.4 Public Financing

(6.4.1) Basis. NAMI California recognizes that the cost of not treating serious mental illnesses greatly exceeds the cost of treating them.

(6.4.2) Public Funding. Public funding for services to persons with serious mental illnesses who are unable to care for themselves is the responsibility of society. Local, state, and federal governments have the responsibility to develop an integrated system of care and to fund this system adequately. Accountability for expenditure of these funds for the priority population must be ensured. Where there is co-mingling of public and private funding streams, accountability measures must be stringent.

(6.4.3) Oversight. NAMI California urges adequate funding to avoid waiting lists and the "dumping" of persons with serious mental illnesses from publicly-funded mental health systems for any reason. On the other hand, indigent, elderly, or other persons with disabilities who do not have serious mental illnesses must not be served in the public mental health facilities.

(6.4.4) Research Related Funding. NAMI California advocates for adequate funding for both biomedical and services research related to serious mental illnesses and for federally-funded treatment and services for individuals with serious mental illnesses. NAMI California insists that these biomedical and services research funds must be awarded to those grants most likely to help persons who have the most severe disabilities. Federal oversight of these grants through national institutes responsible for brain services and treatment research must continue.

(6.4.5) Education Services. NAMI California supports consumer and family education services that enable consumers and families to communicate more effectively with service providers, better understand serious mental illnesses, and develop coping skills. NAMI California believes that community service providers should fund and provide free consumer and family education programs.

(6.4.6) Respite Caregivers. NAMI California supports funding for respite caregivers.

(6.4.7) Federal Mental Health Services Funding. NAMI California must monitor the expenditure of federal mental health service funds in each state. Advocacy efforts must continue to assure that there are regulations at the federal level which require that these funds are spent on services for the priority population.

NAMI California must monitor at the federal and state levels the activities and processes that assure these regulations are implemented. Failure by states to adhere to regulations should result in financial and public penalties.

(6.4.8) Institutions for Mental Diseases (IMDs)

(6.4.8.1) Designation. The federal government currently denies Medicaid reimbursement for persons otherwise Medicaid-eligible who are over 21 and under 65 years of age if such persons reside in facilities designated as "Institutions for Mental Diseases" (IMDs). State hospitals, nursing homes, and residential facilities of 16 or more beds may be classified as IMDs if they provide specialized "mental illness" services, have over 50 percent of their patients diagnosed as "mentally ill," or meet certain other criteria.

(6.4.8.2) Application of Rule. NAMI California believes that the application of the IMD rule most dramatically affects persons suffering from schizophrenia and

other serious mental illnesses because these individuals tend to fall within the impacted age group and thereby are denied Federal Financial Participation (FFP) in their treatment solely on the basis of where they happen to be treated and reside, assuming they would meet all other Medicaid eligibility requirements.

(6.4.8.3)Discrimination. The IMD rule is thus discriminatory and works against the provision of necessary health care for young and middle-aged adults with serious mental illnesses.

(6.4.8.4)Repeal Request. NAMI California calls upon the United States Congress to repeal the IMD rule and to adopt uniform standards of Medicaid eligibility based upon individual resources and the need for services, rather than upon the location in which services are provided or the residence of the recipient.

(6.4.9) Community Reinvestment

(6.4.9.1)Request. If and when public hospitals are no longer needed for the treatment of persons with serious mental illnesses, and such properties are sold or leased, the proceeds should be dedicated to community services for persons with serious mental illnesses.

(6.4.9.2)Public Resources. Public resources and all monies saved by reduced utilization of state hospitals as well as through other system efficiencies should be reallocated to expand community-based services and supports for persons with serious mental illnesses.

(6.4.10) Dual-Diagnosis Funding. NAMI California supports blending mental health, alcohol, and substance abuse funds at the state level for the treatment of persons with dual diagnoses of a serious mental illness and co-occurring substance abuse.

(6.4.11) Developmental Disabilities (DD)

(6.4.11.1)Equal Comparison. Entitlements and programs for persons with serious mental illnesses must compare equitably with those for other physical illnesses and disabilities.

(6.4.11.2)Change Law Request. NAMI California calls for changes in federal, state, and local laws so that those basic services that are presently provided by state and local governments to persons with developmental disabilities are also provided to persons with mental illnesses.

(6.4.11.3)Monitoring and Support. NAMI California encourages monitoring and supporting the activities and procedures of State Planning Council on Developmental Disabilities and evaluating the criteria used by state Developmental Disabilities Councils when reviewing state plans and awarding and implementing grants.

(6.4.11.4)Joint Planning. NAMI California supports cooperation and joint planning between the Center for Mental Health Services and the Administration on Developmental Disabilities and between State Mental Health Planning Councils and State Planning Councils on Developmental Disabilities.

6.5 Managed Care Under All Payers

- (6.5.1) Public Sector Accountability.** The public sector must continue to be accountable for the delivery of treatment and services for persons with serious mental illnesses even when contracting out the services to private sector managed care organizations.
- (6.5.2) Advocacy.** NAMI California advocates for research and services in response to these major serious mental illnesses in persons of all ages: schizophrenia, bipolar disorder, major depression, obsessive-compulsive disorder, and panic disorder.
- (6.5.3) Health Care Eligibility.** There must be continued health care eligibility within the public system for persons with serious mental illnesses who are employed but cannot obtain health coverage through their employers.
- (6.5.4) Support System.** State government must develop and maintain a comprehensive community-support system of treatment and services for the priority populations. State mental health agencies must continue to maintain short- and long-range plans for those with serious mental illnesses. All State Mental Health Plans must contain realistic contingencies for all ranges of ability to pay.
- (6.5.5) Participation.** There must be meaningful participation of consumers and families at every stage of the redesign, implementation, evaluation, and monitoring of the managed care system. All planning and delivery of services must be culturally sensitive to ethnically diverse populations and the communities in which they are located.
- (6.5.6) Managed Care Organizations.** Public sector entities that contract with Managed Care Organizations (MCOs) or other entities for the management and/or delivery solely of Medicaid-funded services for persons with serious mental illnesses must exercise great caution lest they inadvertently divide the mental health system and cause dumping of persons with severely disabling serious mental illnesses who are heavy users of costly services into a public system that is generally considered to be under-funded.
- (6.5.7) Public Resources.** Public resources saved by managed care systems should be reallocated to expand services to the priority population.
- (6.5.8) Provider Personnel.** Provider personnel, both administrators and treatment staff, must have an understanding of serious mental illnesses. They must have training to work with the priority population--including training in the consumer and family perspective--and must accept accountability for the quality of services they provide.
- (6.5.9) Provider Staff.** All provider staff must be rigorously and appropriately credentialed by appropriate state agencies.
- (6.5.10) Community Support Services.** A comprehensive array of community-support services must be available for individuals who meet the priority-population definition for people with serious mental illness regardless of ability to pay. These services must include new-generation medications, inpatient treatment, residential support services, intensive case management, psychosocial

rehabilitation, consumer-run services, and around-the-clock crisis services seven days a week. Outpatient services must be mobile and accessible.

- (6.5.11) MCO Accountability.** MCOs must be held accountable by the public purchasers for linkages to housing with supportive services and employment services.
- (6.5.12) Treatment Planning Involvement.** There must be consumer and family involvement in individual treatment planning including choice of provider, treatment delivery, and appropriate access to peer-support groups.
- (6.5.13) Appeals and Grievances.** Appeal and grievance procedures must be in place that are user-friendly and time-sensitive to the life-threatening nature of psychotic episodes.
- (6.5.14) Purchaser Reporting.** The public sector purchasers must report quarterly to the public the number of recipients who 1) fail to present for services; 2) are in jail or prison; 3) have been placed in a state hospital, nursing home, or other long-term case program; and/or 4) have died.
- (6.5.15) Outcome Measurement.** Outcome measurement for people with serious mental illnesses must be required in contracts with managed care organizations and reviewed by the public sector purchaser on a regular basis. Outcomes should include relevant and scientifically sound measures of clinical status, general health status, functioning, quality of life (such as housing status, employment status, treatment compliance, substance abuse, involvement with the criminal justice system, and involvement with meaningful activities), and subjective measures, such as consumer and family satisfaction.
- (6.5.16) Medicaid Choice of Health Plans.** Choice of health plans should be the primary principle. However, local situations involving histories of poor quality, inadequate numbers of enrollees, possibility of adverse selection, and well-functioning, single carve-out, specialty health plans should allow for waivers to the choice principle.

6.6 Mental Health Parity

NAMI California believes that mental health benefits should be provided in parity with medical and surgical benefits. Mental illness should be treated the same as physical illness, and all mental health appointments, services, and treatments should be as easily accessible as those for physical illnesses. NAMI California believes that the State of California should proactively enforce the Mental Health and Addiction Parity and Addiction Equity Act (MHAPAEA), ensuring that health plans and insurers are complying with regulations based on yearly investigations and reporting, rather than relying on a complaint-based enforcement system.

6.7 Fundraising by Private Agencies

- (6.7.1) Fundraising.** NAMI California strongly encourages governing boards of non-profit agencies serving those with mental illness to undergo aggressive fundraising through direct mail and special events in their own communities regardless of whether their agencies get the bulk of their funds from the state. Community fundraising will not only diversify funding streams of these agencies and augment their programs but also will raise community awareness of the needs of their neighbors with mental illnesses.

(6.7.2) Subtraction of Funds. Under no circumstances should states subtract funds from any agency serving those with mental illness due to separate fundraising efforts by that agency.

7. Research

7.1 NAMI California's Support

(7.1.1) Basis. Neuroscience research, behavioral research, pharmaceutical research, clinical research, as well as service system research are some of the initiatives supported by NAMI California. To this end, NAMI California calls upon the State Legislature, 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 California supports both effectiveness and efficacy-based research, focusing on severe and persistent mental illnesses, especially those with marked burdens of disease. NAMI California expects the rigor and pace of the field of services research to be equal to that of biomedical research.

(7.1.2) Culture. 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, race, religion, ethnicity, 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) Evidence-Based Practices. Given the importance of evidence-based, promising, and emerging practices in the current climate of mental health care, NAMI California 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) Human Subjects.

NAMI California 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) Consent.** 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. We encourage peers to be active in all aspects of research.
- (7.2.3) Involvement.** 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) Consent Protocol.** The consent protocol must provide information that is clear and understandable on an individual basis for each participant and his or her 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) Institutional Review Board Members.** 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.
- (7.2.6) Non-Patient Consent.** 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.
- (7.2.7) Evaluation.** 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.
- (7.2.8) Advance Directives.** 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.

(7.2.9) Institutional Review Board Research Reviewing. 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.

(7.2.10) Consent Withdrawal. 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) Timely Information at Completion. 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) New Medication. 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) Experimental Medications. 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) Biomedical Donation. NAMI California 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) Animal Testing. NAMI California 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) Basis. NAMI California 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

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medications on populations of varying ages, genders, and varying racial and ethnic backgrounds.

(7.4.2) Legislation. With Board review, NAMI California 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) Basis. 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. 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) Recommendation. NAMI California 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, caretakers and friends.

(8.1.2) Advocacy. NAMI California 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) Membership Clarification. While NAMI California 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) Representation.** NAMI California 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 California 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) Consumer and Family Representation.** NAMI California 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) Consumer and Family Participation.** NAMI California 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) Institutional Review Board Membership.** NAMI California 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) Basis.** NAMI California 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 California 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) Regulation.** NAMI California urges the state departments with regulatory authority to enforce the same hospital standards upon the private sector as stated above.
- (8.2.3) Treatment Plan Team.** 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 California believes that the offer, payment, solicitation, or acceptance of a referral fee in relation to delivery of medical services is unethical.
- (8.2.4) Physical Tests.** Physical tests must be incorporated into the intake process. Failure to consider the results of physical tests can adversely impact the mental health treatment.

8.3 Smoking

- (8.3.1) Commitment.** NAMI California is committed to supporting in every way the wellness of people with mental illness and in recovery. NAMI California 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.** 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) Stigma.** 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) Smoke Free and Tobacco Free Environments.** Therefore, NAMI California 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 California opposes any practice that uses access to smoking and tobacco as a form of coercion or reward.
- (8.3.5) Addiction.** At the same time, NAMI California 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) Smoking and Tobacco Recovery.** Therefore, NAMI California 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 California 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) Diagnosis. NAMI California 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 California 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) Support of Laws. NAMI California 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) System Accountability. NAMI California 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) Education. NAMI California 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) Education Development. NAMI California believes that there is a severe shortage of competently prepared professionals in all disciplines to treat persons with serious mental illnesses. 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) Budget Expenditures. NAMI California 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 California believes that all grants must include a pay-back provision for two years of service in a public sector setting.

(8.6.4) Curriculum and Training. NAMI California asks that all academic curriculum and training programs preparing providers to serve persons of all ages with serious mental illnesses include knowledge based on scientific research, proven psychosocial skills for psychiatric rehabilitation in the community, and attention to the development of compassionate, caring, and accepting attitudes towards consumers and their families.

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

(8.6.6) Training and Continued Education. NAMI California requests that all pre-service training and continuing-education programs for providers be multi-disciplinary, culturally diverse, 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. Fellowships must be provided to residents and junior faculty members in child psychiatry programs with adequate financial stipends for their training.

(8.6.8) Urgent Priority Definition. NAMI California 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. 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) Consumer and Family Participation. 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) Spiritual and Religious Inclusion. NAMI California 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) Affirmative Action Endorsement. NAMI California 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) Basis. NAMI California 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, networks, and programs seek accreditation as a means of avoiding at least some of the most conspicuous shortcomings they might possess.

(8.7.2) Self-Study Process. NAMI California 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) Advocacy Against. NAMI CA advocates elimination of the use of seclusion and physical or chemical restraints to control symptoms of mental illnesses. Seclusion and restraint have no therapeutic value, are a cause for human suffering, and have frequently led to both physical and emotional harm, including severe injury and death of adults and children. NAMI CA is in agreement with Substance Abuse and Mental Health Services Administration (SAMHSA) in its “Roadmap to Seclusion and Restraint Free Mental Health Services,” and agrees with the position statements set forth by other mental health advocate organizations, such as Mental Health America and NASMHPD (National Association of State Mental Health Program Directors) and hospitals that have already begun to achieve zero restraint.

(8.8.2) Safety Measurements. While facilities work toward achieving zero restraint, strict safety measurements must be in place. Seclusion or restraint can only be justified as an emergency safety measure in response to imminent danger to the individual or others, and only if all other methods have been exhausted. If exceptional circumstances require restraint, it must be done in the least restrictive manner possible with ample safeguards to protect the person being restrained, and remain in place only so long as, and to the extent that, the individual cannot commit to the safety of themselves and others. Restraint and seclusion 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) Institutional Changes. To achieve zero use of seclusion and restraints, institutional attitudes and methods must change, supported by mandatory training of staff on de-escalation and non-violent methods. NAMI CA advocates establishment of an atmosphere in facilities offering psychiatric care such that seclusion and restraint is regarded as a failure, not as a first response, nor as treatment, nor as a tool for behavior modification or education. NAMI CA urges ongoing education and training of direct care staff in techniques of de-escalation and alternatives to avoid circumstances which might lead to an emergency situation.

(8.8.4) State Oversight. State oversight over seclusion and restraint must be improved and enforced. The state lacks mandatory, consistent and publicly accessible reporting on serious injuries and deaths caused by seclusion and restraint, on the frequency and duration of seclusion and restraint incidents, and on the adequacy of incidents in medical records. The State must establish and enforce clear mandatory standards and requirements for reporting and publication to cover every kind of facility licensed in the state at which such practices have existed or may exist. NAMI CA's position is that publication of such information will aid the movement toward healing and teaching environments free of the violence of seclusion and restraint.

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

(8.8.5.1) Staff Training. 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; 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;

(8.8.5.2) Prohibition of Restraints and Exceptions. 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.

(8.8.5.3) Prohibition of Seclusion and Exceptions. 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.

(8.8.5.4)Multiple Applications. 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);

(8.8.5.5)Prohibition of Disciplinary Techniques. 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;

(8.8.5.6)Prohibition of Restraints as Discipline. 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;

(8.8.5.7)Prohibition of Restraints in Individual Education Plan. Prohibit the inclusion of restraints and seclusion in a student's Individual Education Plan (IEP);

(8.8.5.8)Behavioral Emergency Prevention. 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;

(8.8.5.9)Behavioral Emergency Intervention. 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;

(8.8.5.10) Staff Reporting. 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;

(8.8.5.11) Data Collection. 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 the California Department of Education 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. This action should include training, technical assistance, and corrective action related to any inappropriate use of restraints and seclusion.

(8.8.5.12) Publicly Available Reports. 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

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

8.9 Evaluation of Programs

NAMI CA believes that all programs in the public mental health system should be regularly and rigorously evaluated to ensure best outcomes for those they serve.

(8.9.1) Data Collection. Data collection practices, deliverables, and outcome measurements should be established at the outset of all new programs; consumers, families, and stakeholders must be meaningfully involved in this process.

(8.9.2) State Oversight. Statewide programs should have independent state oversight and accountability mechanisms, including the ability to review program plans, budgets, and outcomes.

(8.9.3) Program Data. Program data must be made available to the public.

8.10 Media Reporting

NAMI California urges the news media to avoid using stigmatizing or inaccurate language when reporting on mental illness, including in reporting on tragic incidences on violence in the community. NAMI CA supports the AP Stylebook guidelines which state:

- Mental illness is a general condition. Specific disorders are types of mental illness and should be used whenever possible.
- Do not use derogatory terms, such as insane, crazy/crazed, nuts, or deranged, unless they are part of a quotation that is essential to the story.

- Wherever possible, rely on people with mental illness to talk about their own diagnoses.
- Avoid using mental health terms to describe non-health issues. Don't say that an awards show, for example, was schizophrenic.
- Do not assume that mental illness is a factor in a violent crime, and verify statements to that effect. A past history of mental illness is not necessarily a reliable indicator. Studies have shown that the vast majority of people with mental illness are not violent, and experts say most people who are violent do not suffer from mental illness.

NAMI California also supports use of the phrase “person who died of suicide” rather than “person who committed suicide”.

9. Legal Issues

9.1 Right to Treatment

(9.1.1) Basis. NAMI California 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) Entitlement of Treatment. With adequate professional consultation, every person with a serious mental illness 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, the substitute judgment of others--subject to sufficient safeguards with frequent review--may be justified in determining treatment and possible hospitalization. Service providers, individuals, and families are urged to work together to develop a plan about whose judgment should be substituted.

9.2 Involuntary Commitment/Court-Ordered Treatment

(9.2.1) Basis. NAMI California 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.

(9.2.2) Belief. NAMI California, therefore, believes that:

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

(9.2.5) Timeliness. 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 in order 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) Qualification of Involuntary Treatment. Involuntary inpatient and outpatient commitment and court-ordered treatment should be used as a last resort and only when cost-benefit analysis shows it to be in the best interests of the individual.

(9.2.7) Standardization Increase. California 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) Gravely Disabled. 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) Deterioration. is likely to substantially deteriorate if not provided with timely treatment; or

(9.2.7.3) Capacity For Understanding. lacks capacity, which means that, as a result of the serious mental illness, the person is unable to reasonably understand his or her need for treatment, care, or supervision.

(9.2.8) Current Law Interpretation. 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) California Law. California law allows for consideration of past history, including that from family members, 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 and must be utilized in every county.

(9.2.10) Independent Review. 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. 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) Emergency Commitments. 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. 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) Justice System Education. Efforts must be undertaken to adequately 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) Health Insurance. Private and public health insurance and managed care plans should cover the costs of involuntary inpatient and outpatient commitment and/or court-ordered treatment.

9.3 Advance Directives and Healthcare Proxies

NAMI California supports efforts of persons with serious mental illnesses, family members, caregivers and service providers to work collaboratively 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 California 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) Data Acknowledgement. NAMI California 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) Consumer and Family Involvement. NAMI California 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) Key Roles. NAMI California 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.

NAMI California 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.

(9.5.4) National Standards. NAMI California 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) Possession of Health Records. NAMI California 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 Requirements. 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 Privacy Protections. 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) Law Enforcement Access. NAMI California 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.

(9.5.9) Legislation for Individual Privacy Rights. 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.

(9.5.10) Referrals. 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.

9.6 The Americans with Disabilities Act (ADA)

NAMI California 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.

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 day a 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 California endorses the principal of therapeutic jurisprudence, which emphasizes that the law should be used, whenever possible, to promote the mental and physical wellbeing 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 Education at All Levels of Judicial and Legal Systems

NAMI California believes that education about serious mental illnesses at all levels of judicial and legal systems is crucial to the appropriate disposition of cases involving offenders with serious mental illnesses. Judges, lawyers, police officers, correctional officers, parole and probation officers, law enforcement personnel, court officers, and emergency medical transport and service personnel should be required to complete at least 20 hours of training about these disorders. Consumers and family members should be a part of this educational process.

10.4 Collaboration

NAMI California 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.

10.5 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.

10.6 Right to Treatment (Regardless of Criminal Status)

(10.6.1) Human and Effective. Humane and effective treatment for serious mental illnesses while in correctional settings is the constitutional right of inmates with severe mental illnesses. NAMI California 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.

(10.6.2) Community Treatment. NAMI California 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.

10.7 Jail Diversion

(10.7.1) Basis. NAMI California 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.

(10.7.2) Support. NAMI California 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).

(10.7.2.1)Crisis Intervention. NAMI California considers the law enforcement Crisis Intervention Team (CIT) Program to be an invaluable tool in diverting persons with serious mental illness toward treatment rather than jail, and expects all law enforcement agencies to develop similar programs.

(10.7.2.2)Support Services. NAMI California encourages the development of mental health courts, which combine judicial supervision with community mental health treatment and other support services in order to reduce criminal activity and improve the quality of life of participants.

10.8 Violence

NAMI California believes that, in the overwhelming majority of cases, dangerous or violent acts committed by persons with serious mental illnesses are the result of neglect or inappropriate or inadequate treatment of their illness. State and local mental health authorities must develop policies and programs to provide care and appropriate treatment for persons who suffer from serious mental illnesses that produce behaviors assessed and labeled by society as “criminal” or “violent.” Where a mental illness and substance abuse co-occur they should be treated with integrated treatment.

10.9 Death Penalty

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

(10.9.1) Circumstances. NAMI California urges California not to execute persons with mental disabilities under the following circumstances:

(10.9.1.1)Onset. Defendants shall not be sentenced to death or executed if they have a persistent mental disability, with onset before the offense,

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characterized by significant limitations in both intellectual functioning and adaptive behavior as expressed in their conceptual, social, and practical adaptive skills.

(10.9.1.2)Impaired Capacity. 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.

(10.9.1.3)Punishment Severity. 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.

10.10 Insanity Defense

NAMI California supports the retention of the “insanity defense” and favors the two-prong (“ALI”)² test that includes the volitional as well as the cognitive standard.

(10.10.1) Guilty but Mentally Ill. NAMI California 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.

(10.10.2) Alternative Terminology. “Guilty except for insanity” and other alternative terminology for the insanity defense

NAMI California 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 statutes³.

² The “ALI test” refers to the rule for insanity adopted in Section 4.01(1) of the American Law Institute’s Model Penal Code. The Code states that “a person is not responsible for criminal conduct if at the time of such 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).”

³ 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

(10.10.3) Informing Juries about the Consequences of Insanity Verdicts. NAMI California 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.

10.11 Solitary Confinement

NAMI California opposes the use of solitary confinement in Secure Housing Units (SHU) for individuals living with mental illness that are incarcerated with the California Department of Corrections and Rehabilitation (CDCR).

SHU inmates spend up to 23 hours per day locked in their cells. Most SHU cells lack windows or direct access to natural light. Inmates are given minimal outdoor time alone in small, separately secured yards. Inmates eat meals in their cells alone. Inmates have limited access to family visits, cannot make phone calls, and are even limited in their ability to have family photos in their cells.

Due to a lack of mental stimulation, psychological research has found that inmates subjected to solitary confinement suffer from a variety of psychological and psychiatric illnesses. For inmates who are already diagnosed with serious mental illness, such confinement severely exacerbates their conditions. We believe that, even when incarcerated, individuals living with mental illness have a right to humane, effective treatment in the least restrictive but secure setting.

10.12 Permission to Reprint

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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.”