

## Outline for Client and Family Driven Transformation of the Mental Health System

### I. Background

During the past decade, the United States has made national progress in advancing mental health policy with the publication of the Surgeon General's Report on Mental Health in 1999, the Supreme Court's decision in Olmstead in 1999, and the President's New Freedom Commission Report in 2003. In California, Senate President Pro Tem Darrell Steinberg has led mental health reform efforts with AB 34, AB 2034, and ultimately with co-authorship of the Mental Health Services Act (MHSA) in 2004.

The MHSA is the culmination of client and family advocacy, both directly and historically, to challenge a history of inequitable, insufficient, unjust and, in some cases, abusive practices. The MHSA replaces this legacy with services and supports informed by a recovery model based in dignity and hope in which clients and families are fully empowered in their communities to move beyond the effects of even the most severe mental illnesses.

The MHSA contains many of the elements of a transformed mental health system. In the following analysis, current MHSA Client and Family Leadership Committee (CFLC) goals for a transformed mental health system are stated, relevant MHSA provisions to those goals are noted, the current status of the goals is summarized, and the CFLC makes recommendations about how to further the achievement of its current goals for a client and family driven transformation of the mental health system.

### II. Elements of a Transformed Mental Health System

#### a. Employment

- i. Goal: Clients and Families are employed in significant roles in the Mental Health System

Goal: Clients are supported to participate fully in the workforce at all stages of recovery

- ii. MHSA provision: Welfare and Institutions Code (WIC) Sec. 5813.5(d) (2) provides, in part: "Planning for services shall be consistent with the philosophy, principles, and practices of the Recovery Vision for mental health consumers: (2) To promote consumer-operated services as a way to support recovery."

WIC Sec. 5822(g) provides: "The State Department of Mental Health shall include in the five-year plan: (g)

Promotion of the employment of mental health consumers and family members in the mental health system."

- iii. Barriers: to persons working in the mental health system, to obtaining a higher ranking position, and to working in general.
  - (1) Individual and organizational stigma; lived experience is not valued.
  - (2) General government bureaucracy; persons with lived experience not included in hiring process.
- iv. Recommendations
  - (1) Develop client and family employment. For example, develop workforce pathways beyond entry level, provide career ladder and educational support.
  - (2) Build in lived experience into quality improvement as added value.
  - (3) Programs set goals for increased lived experience in program.
  - (4) Persons with lived experience should be paid equal to the value they provide. Training and peer support standards should be standardized.
  - (5) Employment outside mental health system needs focus.

b. Policymaking

- i. Goal: Clients and families drive mental health care policymaking  
Goal: Mental health policy is informed by recovery principles, community needs and values and the lived experience of clients and family  
Goal: Clients get what they need to recover in a supportive network of care that is not fragmented  
Goal: Criminal justice and forensic systems are eliminated as entry-points or alternatives to community based mental health supports
- ii. MHSA provision: WIC Sec. 5878.1(a) provides, in part, "It is the intent of this act that services provided under this chapter to severely mentally ill children are accountable, developed in partnership with youth and their families, culturally competent, and individualized to the strengths and needs of each child and their family."  
WIC Sec. 5822(h) provides "The State Department of Mental Health shall include in the five-year plan: (h) Promotion of the meaningful inclusion of mental health consumers and family members and incorporating their viewpoint and experiences in the training and education programs in subdivisions (a) through (f)."  
WIC Sec. 5846(e) provides "The commission shall ensure that the perspective and participation of members and others suffering from severe mental illness and their family

members is a significant factor in all of its decisions and recommendations.”

WIC Sec. 5848(a) provides, in part, “Each plan and update shall be developed with local stakeholders including adults and seniors with severe mental illness, families of children, adults and seniors with severe mental illness, providers of services, law enforcement agencies, education, social services agencies and other important interests.”

- iii. Barriers:
    - (1) Lack of information and education to effectively participate in policymaking.
    - (2) Lack of insight into the value of recovery and client and family issues and voices.
    - (3) Tedium, jargon, technicalities, and confusion discourage participation.
    - (4) Constant flow and shift of policy and information.
    - (5) Lack of funding and planning.
    - (6) Policymakers are not informed or disclosed as clients or family members.
  - iv. Recommendations:
    - (1) Dedicate funding for policy positions and training in advocacy.
    - (2) Provide for continuous dialogue between stakeholders, decision makers and implementors.
    - (3) Encourage people to come out of the closet and be educated in client and family advocacy issues.
    - (4) Provide funding for mentorship for grassroots leaders to become policymakers.
    - (5) Every city/community should fund a client and family taskforce that also participates in regional and statewide advisory bodies.
    - (6) State government should be required to consult with client and family bodies in every issue of mental health and client and family stakeholders should define issues.
- c. Mental Health Programs/Service Delivery
- i. Goal: Move towards recovery/resilience model
    - Goal: Clients and family fully empowered in program settings
    - Goal: Recovery-focused client-run programs and family supports integral part of the ‘system’
  - ii. MHSA provision: the MHSA Section 2(e) provides, in part, “With effective treatment and support, recovery from mental illness is feasible for most people.”

WIC Sec. 5813.5(d) provides “Planning for services shall be consistent with the philosophy, principles, and practices of the Recovery Vision for mental health consumers:

    - (1) To promote concepts key to the recovery for

Individuals who have mental illness: hope, personal empowerment, respect, social connections, self-responsibility, and self-determination.

- (2) To promote consumer-operated services as a way to support recovery.
- (3) To reflect the cultural, ethnic, and racial diversity of mental health consumers.
- (4) To plan for each consumer's individual needs."

iii. Barriers:

- (1) Lack of transportation to meetings.
- (2) Difficulty navigating system, such as knowing where to go for services. Fragmented system results in confusion.
- (3) Fear of whistle blowing because of possible retaliation.
- (4) Lack of dissemination of services, committees, and groups.
- (5) Cultural barriers: geographic, linguistic, and economic.
- (6) Two parallel mental health systems: new MHSA, recovery focused, programs alongside traditional, non-transformed, programs.
- (7) Barriers to employment.
- (8) Economic and organizational resources not available to consumer-run groups.

iv. Recommendations:

- (1) Institute aggressive anti-stigma campaign.
- (2) Recruit, train, and employ underserved populations.
- (3) Provide newsletter to publish meetings, activities, and state and local events.
- (4) Every county should have a client and family task force reporting to the county mental health director on all program planning.
- (5) Bring recovery and resilience models into non-MHSA programs.
- (6) Institute an organizational incubator to support client and family organizations.
- (7) All mental health programs should establish client and family member bodies that approve program planning and design, including hiring executive staff and budgeting at local program level and state level.
- (8) All mental health programs should have a timeline for discontinuing the use of seclusion and restraint.
- (9) Provide for alternatives to crisis services with a "soft intervention" mode.

d. Education

- i. Goal: Education and relevant supports to advance job skills and return to the workforce is viewed as a central to recovery and program design
- ii. MHSA provision: See section 5848(a) above in part c, ii.
- iii. Barriers:
  - (1) Lack of understanding about what to ask for in program accommodations for persons entering education.
  - (2) Stigma for people getting and offering education.
  - (3) No education about career ladders for persons going into workforce, ie. what can be done with lived experience.
  - (4) Lack of learning community; unreasonable expectations of clients.
  - (5) Lack of education and employment towards positions with a living wage.
- iv. Recommendations:
  - (1) Promote peer support and recovery groups on higher education campuses.
  - (2) Provide assessment for “lived experience”.
  - (3) Provide scholarships for persons with lived experience.

e. Community Planning Process

- i. Goal: Clients, families and others involved in served communities set local mental health goals and resource priorities
- ii. MHSA provision: WIC Sec. 5848(a) provides, in part, “Each plan and update shall be developed with local stakeholders including adults and seniors with severe mental illness, families of children, adults and seniors with severe mental illness, providers of services, law enforcement agencies, education, social services agencies and other important interests.”
- iii. Barriers:
  - (1) Fiscal problems in communities
  - (2) Lack of continued engagement
    - a. Information and updates
    - b. Community education
    - c. Publicity and outreach
    - d. Planned stakeholder meetings
    - e. Lack of interest
  - (3) Community burnout
- iv. Recommendations:
  - (1) More outreach and education to:
    - a. Existing stakeholders and other community groups

- i. People with lived experience
      - ii. MHSA Advisory/Steering committees
      - iii. Mental Health Boards
      - iv. Mental Health Advocacy groups
      - v. Law enforcement, justice systems, probation, educators, child welfare organizations, providers, and non-profits.
    - (2) Continuous engagement
      - a. 2-way communication/soliciting and providing information.
      - b. Counties incorporating incoming input into their plans and recommendations.
      - c. Regular planned meetings.
    - (3) More publicity and encouragement for consumer/family member stakeholders to come out and be educated and trained in advocacy issues and MHSA.
    - (4) Engage all community partners to ensure cultural competence.
  - f. Stigma, Abuse and Discrimination
    - i. Goal: Stigma is removed as a barrier to resources for mental health, help-seeking in the public, family well-being and personal recovery in the individual  
Goal: Abusive, dehumanizing and demeaning practices are eradicated from the system of mental health care  
Goal: Discrimination against people diagnosed with mental illnesses and their families is eliminated in health care settings, employment, housing, education, social or civic activities
    - ii. MHSA provision: WIC Sec. 5840(b)(3) and (4) provide “The [PEI] program shall include the following components: (3) Reduction in stigma associated with either being diagnosed with a mental illness or seeking mental health services. (4) Reduction in discrimination against people with mental illness.”
    - iii. Barriers
    - iv. Recommendations
  - g. Prevention and Early Intervention
    - i. Goal: Clients and Families assist with prevention and early intervention of mental illness
    - ii. MHSA provision: WIC Sec. 5840 (b) (1) provides “The [PEI] program shall include...: (1) Outreach to families, employers, primary care health providers, and others to recognize the early signs of potentially severe and disabling mental illnesses.”

- iii. Barriers
- iv. Recommendations

h. Housing

- i. Goal: Improve housing for clients and their families.
- ii. MHSA provision:
- iii. Barriers:
  - (1) Nimbyism
  - (2) Types and amounts of homes available for families and for people to share.
  - (3) Financing.
  - (4) Government regulations, including zoning and rules that prevent families without diagnosis from living in housing.
  - (5) Support services needs for different types of housing; this is an issue when accepting services is a requirement.
  - (6) Lack of property management firms with experience with population and understand and responsible to HUD regulations.
  - (7) Lack of protection of housing when people are hospitalized.
  - (8) Lack of housing available for persons with multiple disabilities: physical, substance abuse and mental illness.
  - (9) Lack of in-home support.
  - (10) Background check for criminal record.

- iv. Recommendations:
  - (1) Form collaborative groups to work on housing projects (partnerships).
  - (2) Provide for peer staff, volunteer and paid, in all types of housing, including crisis housing.
  - (3) Provide for recovery and respite housing as an alternative to hospitalization.
  - (4) Provide for community liaison and education and outreach and engagement for positive visibility.
  - (5) Provide for property manager with identified role as community liaison; employ multiple strategies to engage and educate about stigma.
  - (6) Track information about MHSA housing and other housing.
  - (7) Educate property managers and landlords on working with client populations.
  - (8) Advocate to restructure local zoning.