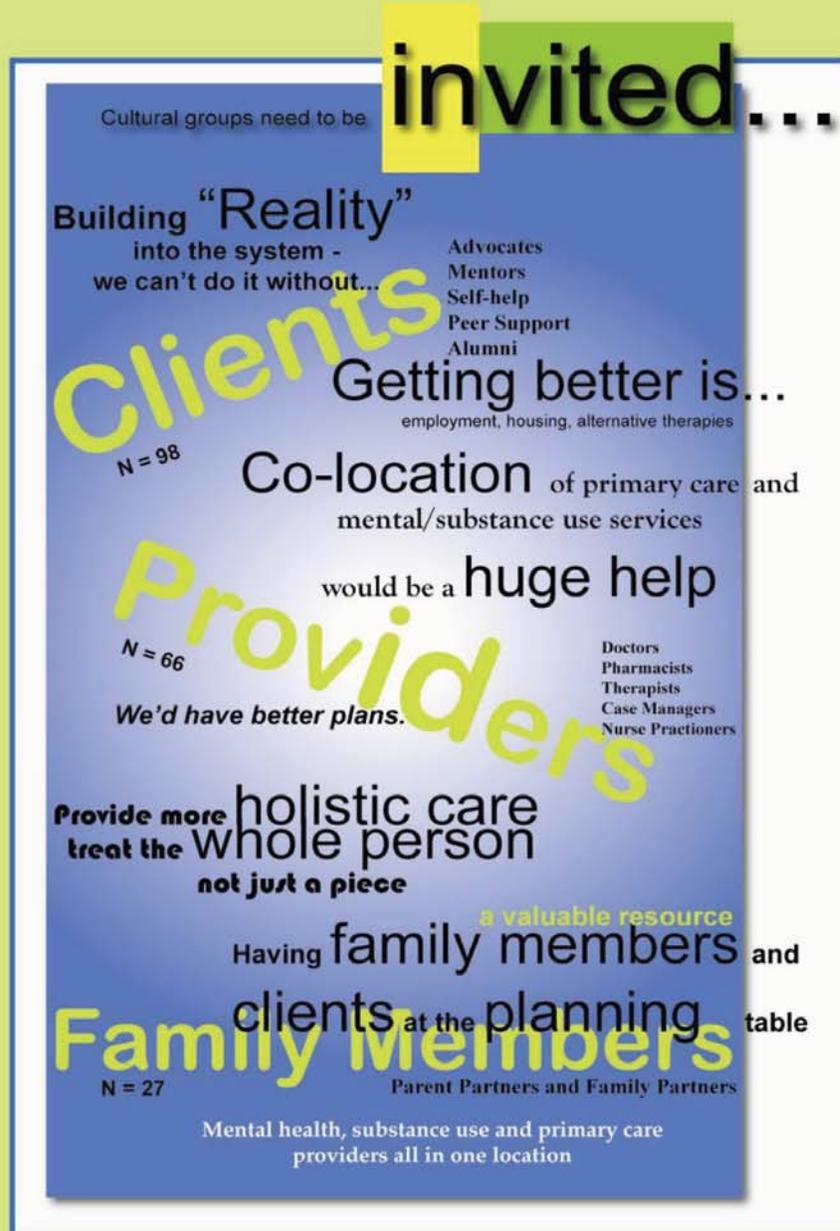


# Integration of Mental Health, Substance Use, and Primary Care Services

*Embracing our Values from a Client and Family Member Perspective*

2011



# Volume 1

## Acknowledgements

### CalMEND Client and Family Member Integration Work Group:

- Alice Washington, BA, Co-lead and CiMH Associate
- Joyce Ott, Co-lead, California Network of Mental Health Clients Coordinator
- Abigail Weissman, MSW, Community Organizer and Planner
- Steve Leoni, Consumer Advocate
- Lea Nagy, Family Member

### CalMEND Client and Family Member Subcommittee:

- Lea Nagy, Lead
- Alice Washington, BA
- Abigail Weissman, MSW
- Joyce Ott
- Steve Leoni
- Paula A. Jones, BA
- Bob Brooks
- Karen Hart
- Hussain Rahim

### Advisors:

- Sandra Naylor Goodwin, PhD, MSW, President and CEO, CiMH
- Gale Bataille, MSW, Emeritus County Mental Health Director, CiMH Consultant
- Ann Evans, MS, Editorial Assistance, CalMEND Consultant

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## Executive summary

The Client and Family Member Integration Work Group of CalMEND developed this issue paper to provide client and family member perspectives regarding the integration of mental health, substance use disorders and primary care. This issue paper is directed to a broad audience of clients/client advocates and family members as well as providers and policy-makers. It is our belief that health care will be accessible and effective only when the diverse perspectives of individuals with “lived experience” and their families are welcomed and fully included in the design, provision and evaluation of services. The reader will notice that this issue paper uses multiple narrative voices, sometimes shifting from a more neutral third person to speaking directly from the “we” voice of lived experience. This reflects our commitment to evidence and identification of best practice as well as our passion regarding the health crisis that is causing the physical illness and early deaths of individuals with serious mental illness.

This issue paper provides resources and tools to support wellness and recovery, and to keep hope alive for clients (and their families) so that they can achieve both mental and physical “total wellness.” We also advocate for the inclusion of clients and families that represent our diverse population in local planning and implementation of integrated health care. In preparing this report, we were guided by the mantra of the mental health recovery movement: “Nothing About Us, Without Us.”

In spite of the shockingly shortened lifespan of people with a serious mental illness (SMI), including those with co-occurring substance use (SUD) and physical health issues (COD or co-occurring disorders), clients and family members have some good reasons to be hopeful:

- Heightened awareness and research about the increased morbidity and mortality of people with serious mental health problems has generated attention, discussions, campaigns, and some positive change in service delivery.
- Increased morbidity and mortality associated with SMI are largely due to **preventable medical conditions**. Not only are metabolic disorders, cardiovascular disease, diabetes mellitus, respiratory diseases, and infectious diseases preventable, but suicide is as well.
- Clients have the ability to modify risk factors such as obesity and smoking that contribute to medical conditions and thus have the potential and power to enjoy healthier and longer lives.
- Risk monitoring and treatment guidelines are underutilized for SMI populations. Educated clients and family members and other advocates can take action to ensure equitable application/use of risk monitoring and treatment guidelines.
- Some psychiatric medications contribute to health risks. Clients and family members can develop alternatives to address the health risks associated with certain medications through working closely with prescribing health care providers.
- Clients can use self-management tools such as Whole Health, Recovery Dialogues and Wellness Recovery Action Plan (WRAP) to improve their mental and physical health.
- We can set our own goals and collaborate in creating plans to achieve them.
- California’s Mental Health Services Act (MHSA) calls for a major transformation: mental services are to be client and family member driven. The MHSA sets a new expectation that client and family members are involved in local planning, and we have the opportunity to promote this new expectation of active engagement in planning for health as well as behavioral health services.

### An overview of the paper...

**THE PROBLEM:** People with SMI, SUD, and COD and their families, along with the public health care systems that serve them, face an urgent need to decrease the dramatic disparities in mortality and morbidity of those who have SMI, SUD, and COD and the rest of the population.

In response, national, state and local organizations are addressing the need to bridge the gaps between primary health care and behavioral health care...

**Some form of integration is seen as the best path to enhance and improve (a) quality of care; (b) quality of life; (c) access to care; and (d) cost containment/budget constraints.**

We discuss core values that must guide and shape integrated care planning and implementation.

**OVERARCHING VALUES:** The values of person-centeredness and recovery must be developed and supported in person-centered health care homes and any other integration of care initiatives. We discuss MH/SUD core values that should be sustained as well as new core values necessary to support recovery-based care for clients with mental health issues and/or substance use disorders.

The voices of clients and family members are important in shaping integrated care. The CalMEND Client and Family Member Integration Work Group provides recommendations for engaging in local planning for integration of care.

**PARTICIPATING IN LOCAL PLANNING:** As California moves towards implementation of the California 1115 b Medicaid Waiver and national health reform, including person-centered health care homes, local health organizations (both public and private) are involved in planning and designing new systems which must involve client and family member participation.

In the last section of this report, we highlight the perspectives of stakeholders through sharing key results of a survey of clients, family members and providers on their experience and concerns about integration. Although the survey was relatively small (and does not represent a random or stratified sample) respondents' perspectives and concerns are important and bring life to our perspectives as presented in this paper.

We wish you a productive journey down the path of wellness and recovery as we explore key issues and concerns regarding integration of mental health, substance use, and primary care.

# Section 1

## Background

The relatively recent movement to integrate primary care with behavioral health care – including both mental health and substance use – is largely a response to the National Association of State Mental Health Program Directors (NASMHPD) 2006 report:

Recent data from several states have found that people with serious mental illness served by our public mental health systems die, on average, at least 25 years earlier than the general population.

Even worse, the disparity between the life span of those with and without serious mental illness (SMI) has increased exponentially. In the early 90s people with SMI died an average of 10–15 years earlier than others compared to the more recent statistic of 25 years.

A more recent report authored by Barbara Mauer, *Substance Use Disorders and the Person-Centered Health Care Home*, provides an important focus on individuals with co-occurring disorders – mental health and substance use.

“Indeed, the population with co-occurring MH/SU disorders may be the most at risk. Nearly 60% of individuals with bipolar disorder and 52% of persons with schizophrenia have a co-occurring SU disorder. Approximately 41% of individuals with an alcohol use disorder and 60% of individuals with a drug use disorder have a co-occurring mood disorder. According to an Oregon study, those with co-occurring MH/SU disorders had an average age at death of 45 years...” (pg. 5, Mauer).

This paper asks the reader to understand the seriousness of these health disparities and calls upon clients, family members and providers to join in the crafting of solutions.

The increased morbidity and mortality rate of people with serious mental health and substance use problems – with decades of life lost – is both well-documented, and unacceptable. It is essential to note that

preventable health conditions such as cardiovascular disease, metabolic disorders and diabetes cause the majority of these early deaths. Below is an excerpt from Christine Reardon’s excellent summary of the *NASMHPD 2006 Report on Morbidity and Mortality Associated with Serious Mental Illness*.

“Taking steps to stay healthy – eating right, getting enough exercise, following medical advice – can be challenging for anyone. But for people who also struggle with mental health conditions, the task can seem nearly impossible. It may be difficult to prepare nutritious meals; psychotropic medications may cause weight gain; visits to crowded and fast-paced doctors’ offices can bring on anxiety and frustration. And the consequences can be deadly...” (pg. 14, Reardon).

In response to these dire statistics, national, state, and local organizations are addressing the need to bridge the gaps between primary health care and behavioral health care. Those involved include: professional associations such as the National Association of State Mental Health Program Directors, researchers and think tanks; advocates for people with SMI, SUD, and COD. In California, organizations include the California Institute for Mental Health, California Mental Health Directors Association, the California Association of Alcohol and Drug Program Administrators, and the authors of this paper, the CalMEND Client and Family Member Integration Work Group.

The Substance Abuse and Mental Health Services Administration (SAMHSA) is providing key leadership in making MH/SUD health disparities visible – including the 10X10 Wellness Campaign. In 2010 SAMHSA launched the campaign “to promote the importance of addressing all parts of a person’s life in hopes of increasing life expectancy for persons with mental health, SUD, and COD problems by 10 years over the next 10 years.”

Some form of integration is generally understood to provide the best path to enhancing and improving (a) quality of care; (b) quality of life; (c) access to care; and (d) reduce costs over time. A recent report to Congress, *National Strategy for Quality Improvement in Health Care March 2011*, Section 3, states the following:

“Promoting Effective Communication and Coordination of Care...

When all of a patient’s health care providers coordinate their efforts, it helps ensure that the patient gets the care and support he needs and wants, when and how he needs and wants it. Effective care coordination models have begun to show that they can deliver better quality and lower costs in setting that range from small physician practices to large hospital centers.

Health care systems need to encourage coordination and help providers care for patients with chronic diseases so they get the kind of seamless care that is most effective...” (DHHS, 2011).

The transformation that is required to integrate care is complex and includes developing computerized records and health information exchange, re-training providers, addressing cultural differences between primary care, mental health and substance use services, developing new policies, creating new payment/financing provisions, etc. Professionals from many

arenas support integration as the best solution and offer possible methods to achieve it. Integration of care is a core tenet in the Affordable Care Act (ACA) of 2009. California and other states and localities across the country are designing, implementing and assessing the effectiveness of various models of integrated care. Although the movement to integrate care is well underway, full integration of care is multi-faceted and will necessarily take time.

Nonetheless, a **consensus has been reached**. Integration of primary care and behavioral health services is the **system choice** to address high mortality, morbidity and suicide rates for people with SMI, SUD, and COD who are served by our public mental health systems. New integration practice models are emerging: primary health care in behavioral health settings, including both mental health and also substance use; increased behavioral health services in primary care; and stepped care partnerships among primary care and behavioral health organizations. Christina Reardon summarized this consensus: “Strong behavioral health/primary care partnerships can create person-centered health care homes where those with serious mental illness can receive the best care” (pg. 14, Reardon).

SAMHSA has provided a valuable resource to increase our understanding of health care reform that can be accessed through webinar links that are shown in the reference list at the end of this paper, Volume 1.

# Section 2

## Core values must guide and shape integrated care: Recommendations from the CalMEND Client and Family Work Group

**OVERVIEW:** This paper advocates that the values of person-centeredness and recovery must be fully included in health care homes and other models of integrated care. The following discussion outlines core values that should be sustained and in some cases developed; identifies new core values; and, provides tools that can promote recovery-based care for clients with mental health and/or substance use disorders.

**We endorse and embrace integration of mental health, substance use, and primary care. Where possible, MH/SUD and primary care services should be integrated within a health care home. When greater intensity of MH/SUD services is required, care needs to be “stepped” and coordinated between the health care home and a specialty MH/SUD provider.** Integration is not only the **system choice**; it is the choice of many, perhaps most, clients and family members to combat increased morbidity and mortality rates as long as we are involved in every step of this necessary transformation. Our chorus remains the same mantra our family members and we, mental health clients, have been repeating for many years: **NOTHING ABOUT US, WITHOUT US.**

We have found our voice. We and our families of choice are the experts on our own lives, wants and needs. Health care providers, including psychiatrists, primary care and other physicians, mental health clinicians, peer specialists, chemical dependency counselors, and nurse practitioners must partner with us to support our goals for healthy and meaningful lives. Increasingly, clients and the behavioral health care providers who serve us are learning to collaborate. This collaboration will be challenging, particularly in the short run, as integration proceeds and primary care providers, clients and their supporters, and behavioral health care providers learn to work as a team.

### Develop, maintain and sustain our established core values to guide integration

There are current and developing integration models, as outlined in the Milbank Report, “Evolving Models of Behavioral Health Integration in Primary Care” (page 14), that are consistent with our established core values. Although we are not recommending any particular integration model, we do want to highlight core values that should be included in any local planning process related to integration services.

1. Person-centered
2. Recovery-based
3. Wellness-focused
4. Family inclusion
5. Cultural inclusion and cultural humility

### CORE VALUE 1: PERSON-CENTERED

Our first core value is that of person-centeredness. The **concept** of “person-centered” is distinct from any particular model. The concept is applicable in any health care practice – MH, SU, and PC. It represents a paradigm shift from the traditional physician-directed relationship to a collaborative team and partnership between client and provider.

What are the key developments in person-centered care? As early as 2002, the American Medical Association (AMA) published “*Patient Self-management of Chronic Disease in Primary Care*” as part of its series on “*Innovations in Primary Care.*” This paper introduced the Chronic Care Model.

The CalMEND initiative has developed and adopted a modification of the Chronic Care Model in several learning collaboratives in order to emphasize not just an “activated patient” but an “informed and empowered client and family.” This adapted model is shown below. The model indicates that improved outcomes are achieved when clients and family members part-



ner with a health care team in productive interactions that are: person-centered, timely and efficient, coordinated, evidence-based and safe.

In 2002, integration of health care was only just beginning to be part of the conversation about the need for a paradigm shift from chronic disease care to a more collaborative model. This shift served as a precursor to today's integration values.

TWO KEY PARTS OF THE PARADIGM SHIFT:

**1. Collaborative care** recognizes that the patient/client is the expert in his/her own life and that he/she can interact with providers (and family members) as partners, building upon the knowledge and strengths of each. This key part of the new paradigm includes patient/client shared decision-making.

**2. Self-management support and education** teaches problem-solving skills. The goal of self-management support is to build on client/patient choice and motivation in contrast to traditional patient education that has its goal "compliance with the behavior changes taught to the patient to improve clinical outcomes."

What was considered "innovative" in 2002, i.e. patient self-management, is now becoming mainstream and is highlighted as a cornerstone of quality in the first "Report to Congress: National Strategy for Quality Improvement in Health Care March 2011."

The *National Strategy for Quality* states that three "interrelated and mutually reinforcing" broad aims are: better care, healthier people and communities, and affordable quality care for all. "Ensuring Person- and Family-Centered Care" is the second of the six aims

described. The report clearly supports the critical and active role of clients and families in determining their care:

“Health care should give each individual patient and family an active role in their care. Care should adapt readily to individual and family circumstances, as well as differing cultures, languages, disabilities, health literacy levels, and social backgrounds.

This kind of person-centered care, which sees a person as a multifaceted individual rather than the carrier of a particular symptom or illness, requires a partnership between the provider and the patient with shared power and responsibility in decision making and care management.”

The idea of shared power and responsibility is fundamental in decision-making and care management and sets the stage for the meaningful inclusion of clients and family members in local planning and implementation of integrated health care.

## **CORE VALUE 2: RECOVERY-BASED**

Recovery is an essential foundation for mental health and substance use care. Clients and the client recovery movement provide the sustaining power behind the recovery vision. Below we outline a vision of recovery for those with mental health issues and for those with substance use disorders. It is important that we sustain recovery as a core value in any shift toward integration of behavioral health and primary care. The loss of the recovery vision could shift our system back to a medical model that disempowers clients and families. We encourage the use of the recovery resources and tools as local-level planning for integration is implemented.

### **The roots of recovery from alcohol and drug use**

Alcoholics Anonymous (AA), begun in the 1930s, first popularized the word “recovery” as it pertains to chemical dependency. **AA also provided the world with an early model of integrated treatment for body, mind, and soul.**

According to the first written text of this movement, **Alcoholics Anonymous**, recovery means not only physical sobriety but also restoration to sanity

through taking the 12 steps. The principles underlying those steps are honesty, hope, faith, courage, integrity, willingness, humility, compassion, balance, perseverance, spirituality, and service. Step 12 provides recovering members with a new life purpose: to carry the message of AA to other alcoholics and to practice the principles named above in all of one’s affairs.

Anyone attending a 12-step meeting is privy to evidence that recovery is possible by listening to others who have stopped using their drug of choice. Members who have already taken the steps and who no longer use alcohol or drugs freely share their experience, strength and hope with others who want their support to take the steps.

In addition, the inclusion of friends and family members affected by people with substance use disorders began over 55 years ago.

“...Al-Anon (which includes Alateen for younger members) has been offering strength and hope for friends and families of problem drinkers. It is estimated that each alcoholic affects the lives of at least four other people... alcoholism is truly a family disease. No matter what relationship you have with an alcoholic, whether they are still drinking or not, all who have been affected by someone else’s drinking can find solutions that lead to serenity in the Al-Anon/Alateen fellowship.”

For more information go to <http://www.al-anon.alateen.org/index.php>

### **Mental health recovery**

Mental health recovery is best explained through stories of lived experience (see Steve Leoni statement on page 8).

On December 16-17, 2004, SAMHSA and five other federal agencies convened more than 110 expert panelists, including clients, family members, providers, advocates, and others in order to develop a clear definition of recovery. The *SAMHSA National Consensus Statement on Mental Health Recovery* states:

“Mental health recovery is a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a commu-

### Steve Leoni, Consumer Advocate

Recovery is about more than “getting better” or learning self-management techniques. It is about those things and others...but for many it is most importantly about healing – a lack of wholeness and becoming a person again.

What is the meaning of what was just said?

**“You would have had to have been there.”**

Your mind and emotions are, in many ways, You. When your mind receives a medical diagnosis, your mind becomes a medical object. Your mind, in the form of You, is treated by those around congruently with that of object status. Your life becomes, over time, defined by this new, non-social definition of yourself, constantly reinforced by those round you. Shame plays a role, too. Shame is almost the only way you can now be socially appropriate. Many seek to avoid the pain of this shame by denying their illness, others by accepting the object status and lowering their self-expectations. Often, they effectively do both. There is isolation from the social mainstream. If your symptoms are obvious, you face the patronizing and, sometimes, fearful rejection from stigma and discrimination – sometimes, even by the professionals treating you. If your symptoms are not obvious, you live in guilty fear of being discovered. Your new identity, in conjunction with the symptom challenges that you have, leads you to feel that you are no longer the person you once thought yourself to be. You are now something much less than that reduced to preoccupation with your own un-wholeness.

Hence, for many, recovery is about getting your humanity back, whether or not your symptoms have all gone away.

nity of his or her choice while striving to achieve his or her full potential” (SAMHSA, 2004).

The expert panelists defined 10 fundamental components of recovery as reprinted from the SAMHSA consensus statement:

### 10 Fundamental Components of Recovery

Self-direction  
 Individualized and person-centered  
 Empowerment  
 Holistic  
 Non-linear  
 Strengths-based  
 Peer Support  
 Respect  
 Responsibility  
 Hope

### CORE VALUE 3: WELLNESS-FOCUSED

Recovery as understood in Core Value 2 is *not integrated into the culture of primary care and requires the additional core value of wellness-focus*. Whereas, the field of chemical dependency and/or mental health recovery is understood to be a process and not a quick fix, in traditional primary care, especially in the age of insurance company managed care, the process of “recovery” typically consists of a brief visit to the doctor about a current symptom/problem for which the doctor provides a solution, most often a medication prescription, or recommendation for further tests to determine a diagnosis and further treatment. This very different and episodic primary care treatment approach is a cause for individuals with SMI/SUD to ask:

- How can we bridge significant differences in organizational culture between MH/SUD and primary care provider?
- How can we overcome the structural and economic barriers in primary care that run counter to the recovery-orientation?

For example, primary care providers (PCP) are not paid to spend much time with patients. If they don’t work quickly, public as well as private PC practitioners face very real economic difficulties. Medicare, Medi-Cal, and private insurance companies reimburse in amounts so low that it would appear they

**Recommendation:** Integration of care/whole health also requires that we adopt and promote new values: Reunite mind-to-body connections through integration of primary care, mental health care, and alcohol and other substance use care

expect providers to spend only a few minutes with each patient.

If these concerns are to be addressed, more resources (including time for client/patient care) training and other strategies must be used to shift the culture of primary care to understanding and adopting a recovery-orientation. In addition, MH and SUD providers must become more effective in coordinating care with primary care providers. (NOTE: Useful tools and resources are listed in below and in Section 3 of this paper.)

### **New models that support the core value of wellness through whole health and person-centered health care homes**

Integrated systems increase opportunities to connect body, mind and soul. Effective integration of behavioral health and primary care supports this new value – care for the whole person. The Person-Centered Health Care Home, which is a core concept in health care reform, can potentially help organize, provide and coordinate care for the whole person. Mental health and substance use prevention and treatment must be considered core services of person-centered health care homes.

A succinct rationale for including mental health and substance use services in the Person-Centered Medical Home (PCMH) is articulated by Pamela Hyde, Administrator, Substance Abuse and Mental Health Services Administration:

- Behavioral health is part of health.
- Prevention works.
- Treatment is effective.
- People recover.

Models of integration are evolving at a fast pace nationally and in California, especially as we move to implement the California 1115 b Medicaid Waiver and the Affordable Care Act. We must be aware of the diversity of individual and community needs and resources. The CalMEND Client and Family Integration Work Group reviewed different models and structures for care integration, but elected to not recommend any particular models. We do, however, strongly recommend that client and family centered/driven needs and core values be clearly articulated as a necessary framework for Person-Centered Health Care Homes.

It is heartening to find that a recent publication from the federal Agency for Healthcare Research and Quality on “The Patient Centered Medical Home: Strategies to Put Patients at the Center of Primary Care” advocates for the inclusion of patients/clients in their own care, in quality improvement, and in the development of policy and research (AHRQ, February 2011).

“Evidence exists regarding the benefits of engaging patients in their own care, but more research is needed to identify sustainable approaches and ways to adapt these approaches to various primary care settings. Little evidence is available regarding the effects of engaging patients in practice-level QI or in policy and research. Useful examples do exist, however, of innovators engaging patients at all three levels.”

We endorse and urge state and local integration planning initiatives to take further steps and include recovery-oriented principles and values such as those articulated in the following projects/initiatives:

1. The core attributes that were developed as the *Oregon Standards and Measures for Patient-Centered Primary Care Homes*

#### ACCESS to CARE

Be there when I need you.

#### ACCOUNTABILITY

Take responsibility for making sure I receive the best possible health care.

**COMPREHENSIVE WHOLE-PERSON CARE**  
Provide or help me get the health care and services I need.

**CONTINUITY**  
Be my partner over time in caring for my health.

**COORDINATION AND INTEGRATION**  
Help me navigate the health care system to get the care I need in a safe and timely way.

**PERSON- AND FAMILY-CENTERED CARE**  
Recognize that I am the most important member of my care team and that I am ultimately responsible for my overall health and wellness.

2. The value of whole person and community health as reflected in the “healthcare neighborhood”.

The “Healthcare Neighborhood,” a Fulton County, Georgia, one-stop shopping center, includes the following:

(Fulton County, Georgia, 2011):

Well-patient care

Sick-patient care

OB/GYN services

Travel immunization services

WIC/nutrition education

Oral health services

MH/SU health services

A day center for parents receiving service

Employment assistance

Disability and vocation rehabilitation services

Foreclosure prevention services

Housing assistance

A reading room/information center that offers

ESL classes

A farmer’s market

A community garden

A walking trail

3. Underlying core beliefs as stated in the *Peer Support Whole Health Training Manual*. (Appalachian Consulting Group, Inc., 2009)

People cannot be forced or coerced to change their unhealthy life-style habits; therefore, participation in the PSWH training needs to be on a voluntary basis and participants acknowledge that they have health issues that they are thinking about dealing with.

People are more likely to create a healthier life-style when you focus on their interests, strengths, supports and what they see as possible; therefore, the PSWH training helps people focus on what they want to create in their lives, not on what they need to change.

People find it easier to create new habits than to change or stop old habits.

SAMHSA has provided a valuable resource to increase our understanding of the person-centered health care home that can be accessed through webinar links listed in the reference list.

#### **CORE VALUE 4: FAMILY INCLUSION**

Families must be recognized and included as key supporters and members of each individual’s care team. The inclusion of parents is mandatory for young children, but is also essential to clients who wish to designate “family members, friends, caregivers and other relatives,” who can support, advocate and provide “hope” in their recovery journey.

Family collaboration is very important in person-centered care. Family members can help provide essential links between the primary care practitioner and mental health or substance use care. Engaged families are key to better communication.

There has been a significant change in past perspectives on the role of families. Discredited historical views of families as causing illnesses, meddling in the lives of clients, angry and irrational have been replaced with a new understanding. Today, families should be understood and respected as partners in care, advocates for better health care reform, holding “hope and empathy” for loved ones with mental

illness, and as potential problem solvers (not problem makers) in systems of care.

Families are valuable partners in the recovery journey, providing emotional and other tangible supports to individuals who are working to develop and sustain healthy lifestyles that reduce high mortality and morbidity rates due to treatable physical health issues.

### **CORE VALUE 5: CULTURAL INCLUSION AND CULTURAL HUMILITY**

The integration of MH/SUD within primary health care is generally understood to increase access and reduce the experience of discrimination and stigma that is associated with the use of mental health and addiction services – especially for diverse ethnic, linguistic and cultural communities. For certain cultural communities, concepts of mental health and mental health treatment either do not exist, or are very different than Western concepts of mental health and mental illness. Some innovative practices have integrated mental health with both physical medicine and traditional healing approaches. When integrated primary care-based services address MH/SUD in the context of total health care, diverse populations experience greater cultural inclusion at both the individual and the family/community level.

In their article, “Managing Cultural Differences,” Anastasia Bibikova and Vadim Kotelnikov state:

“Culture in general is concerned with beliefs and values on the basis of which people interpret experiences and behave, individually and in groups. Broadly and simply put, ‘culture’ refers to a group or community with which you share common experiences that shape the way you understand the world.

Some of the most significant and challenging components of cultural programming include our beliefs, values, expectations, attitudes, and assumptions. Our cultural programming

in these areas shapes everything we do. Most importantly, they help us to decide what is ‘normal’ in our eyes. It is the perceived deviation by other cultures from our version of normality that causes the problems. In short, ‘us’ and ‘them’ live on.

We must also recognize that an individual can identify with multiple cultures, depending on his or her birthplace; nationality; ethnicity; family status; gender; age; language; education; physical condition; sexual orientation; religion; profession; place of work and its corporate culture. Culture is ... central to what you see, how you make sense of what you see, and how you express yourself” (Bibikova et al., 2011).

Tervalon and Murray-Garcia advocate for the teaching and inclusion of “cultural humility” as a core value and process in the training (and practice) of pediatric and other physicians. However, it is also a critical value for bridging of patient/clients’ cultures and professional cultures necessary for the true integration of care.

“Cultural humility incorporates a lifelong commitment to self-evaluation and critique, to redressing the power imbalances in the physician-patient dynamic, and to developing mutually beneficial and non-paternalistic partnerships with communities on behalf of individuals and defined populations” (Tervalon et al., 1998).

Cultural inclusion and cultural humility are key values not just in the direct provision of care, but are also critical values in supporting MH/SUD clients and their families to be “at the table” as integrated systems of care are planned, implemented and improved over time.

The University California, Davis, School of Medicine has provided a valuable resource to increase our understanding of cultural competence that can be accessed through webinar links that are shown in the reference list.

# Section 3

## Recommendations for engaging in local planning for integration of care

**OVERVIEW:** As California moves towards implementation of the California 1115 b Medicaid Waiver and national health reform, including person-centered health care homes, the local health organizations (both public and private) that are involved in planning and designing new systems must include clients and family members in their process.

We respectfully assert that our health and primary care partners must develop a greater understanding and appreciation of the benefits of including clients and family members in the planning and design of these new systems. The client and family survey results in Volume 2, provides feedback from our communities, including many that voice their concerns about losing the commitment to a vision and principles of wellness and recovery as behavioral health services are integrated with primary care. Why? Two respondents state, “Yes... stigma is very strong in the primary care community” and “I am afraid my care will suffer.”

As we integrate the fields of mental health, substance use and primary care, it is critically important to educate, train, and engender responsibility with a goal of improving clients’ and family members’ quality of life through community building and the reduction of stigma and discrimination.

**Understand that clients’ and family members’ values do affect “real” outcomes for local services, and it is critical that we are all active leaders and participants in local-level integration planning.**

Our strongest recommendation is also the simplest to achieve: Encourage clients and family members to **SHOW UP** for local integration planning processes!

Some clients and family members choose to be occasional observers/participants in public meetings and

### Steve Leoni, Consumer Advocate

Evidence base, as understood today, has been largely missing, historically, from mental health and has only gained significant ground in recent years. Prior generations’ care was largely based on theoretical considerations grounded for the most part on collective provider/academic opinion e.g., Freudian views, views that clients could not know what was helpful to them, views that family members were the cause of clients’ mental illnesses.

Modern scientific research has tended to validate viewpoints, concerns and insights from clients and family members that differed from the received clinical opinion, which is a major reason why these groups carry weight within the transforming mental health community.

Even today, there are remnant attitudes and clinical actions in use in the mental health community that ultimately trace their roots and justification back to the clinical concerns and ideas of those earlier days. Changing those attitudes and actions, along with continuing to learn what really works, is the focus of current ongoing efforts in mental health system transformation.

Given the transformation within mental health itself, physical healthcare needs to transform as well with respect to mental health care and issues. Historically, primary care providers have not received substantial training on dealing with the mental health side of the person that is treated and much of the information they have received is out-dated, often with subtle clinical remnants. Also, in the relative absence of training, primary care is not immune to the misinformation rooted in stigma that commonly occurs in the public and media discourse on mental health issues.

planning processes, and that is truly helpful. When county officials see many different faces of interested clients and family members, they get a visual sense of those to whom they are accountable. The mere presence of clients and family members is a good reminder that the process must be transparent and open to service recipients and their supporters. Even if as clients and family members, we haven't studied the issues and/or formed opinions, we can learn by attending. Furthermore, our very presence at local planning meetings conveys our main message: NOTHING ABOUT US, WITHOUT US.

Before we address more specific strategies for effective client and family member participation in local planning, it is important to acknowledge and understand that strategies may differ across diverse cultural communities.

In their article, "Managing Cultural Differences," Bibikova and Kotelnikov note that culture is often at the root of communication challenges. Differences in cultural communication also impact how diverse and underserved communities may participate in local planning for health system change.

Our client mantra, "Nothing About Us, Without Us" may not translate into empowerment for some cultural communities that are invited to integration planning and implementation – especially for those cultures in which the physician is viewed as the authority and the MH/SUD recovery movement's history of advocacy for the values of person-centeredness and recovery-orientation is not part of a particular group's cultural history or tradition. We must acknowledge and respect these diverse perspectives. The CalMEND Client and Family Member Integration Work Group survey (discussed in Sections 4, 5 and Volume 2 of this report) includes some important suggestions on how to involve un- and under-served cultural groups:

"Cultural groups need to be invited or accessed through their own communities: such as cultural events, cultural centers, places of worship or places they gather. Information passed through media, radio, in front of ethnic markets, newspapers, advertisement in public transportation, as to inviting them to be involved, must be in

their languages to ensure everyone is aware of the health care reform..." —Santa Clara County

**But showing up is not enough. We also need client and family members who are more than occasional observers. Therefore, the CalMEND Client and Family Member Integration Work Group has developed recommendations that can support and empower all clients, family members, and providers of MH/SUD/PC for local integration planning and implementation.**

The recommendations that follow represent the collective thoughts of our work group for this paper. The group consists of clients, family members, and providers. Several of the clients and family members have also worked as providers in various capacities. Our technical advisor is a former director of a county behavioral health department in California.

Decisions about whether and how to use any of our suggestions for involvement and what specific recommendations you make during your local planning for health care reform are up to you as readers of this paper. We respect the wisdom that results from collaboration at the county level, based on unique county needs and your own innovative solutions.

We've assigned our recommendations to these general categories:

- I. INTEGRATING CARE AT THE POLICY AND PLANNING LEVELS
- II. INTEGRATING MH/SUD AND HEALTH CARE AT THE PRACTICE LEVEL
- III. SELF ADVOCACY/SELF MANAGEMENT SUPPORT

## **I. INTEGRATING CARE AT THE POLICY AND PLANNING LEVELS**

In order to work effectively with county officials, local health care integration committees, planning committees for Medicaid 1115 b Waiver implementation, MHSA steering committees and/or other groups making decisions about expenditure of MHSA funds, advisory boards, mental health boards, etc., you need to become better educated about integration as well

**Recommendation:** The California Institute for Mental Health has developed tools that can be used to understand integration and for local level engagement in planning including “The Business Case for Bi-Directional Integrated Care.” For more information go to: <http://www.cimh.org/Initiatives/Primary-Care-BH-Integration.aspx>

as changes that are coming down the pike with the passage of national health care reform. Some methods to learn more about these topics include getting on the listservs such as Mental Health America, SAMHSA, and the DHCS 1115 b Medicaid Waiver and visiting websites that address integration and whole health, such as the websites of SAMHSA and National Council Center for Integrated Health Solutions.

Here are some strategies or actions that clients and family members might take to become more effective in influencing local planning for integration and health care reform:

- Learn how to become effective committee members
  - ✓ Ask if your county pays for training in how to become effective board members and/or county committee members/leaders
  - ✓ If not, look for mentors and/or invest in the training yourself
  - ✓ Read about how to be an effective part of a board online or borrow books from the library.
- Take actions to maximize your influence on local-level integration planning and implementation. Some basic strategies include:
  - ✓ Attend meetings frequently;
  - ✓ Prepare ahead of meetings by requesting and reviewing minutes and handouts from previous meeting(s);
  - ✓ Submit written opinions to mental health board members, integration and/or health care reform planning groups, and key behavioral health county officials;
  - ✓ Compare policy decisions with written documents submitted by client and family member groups. When appropriate, request explanations for discrepancies;
  - ✓ Coordinate with other concerned citizens ahead of and after local-level county meetings.
- Attend and/or become formal members of a planning committee, county work group on integration of the Department of Health Care Service’s 1115 b Medicaid Waiver (Bridge to Health Care Reform). Regular participation over time builds credibility, develops relationships with county officials and other participants, and helps us influence plans and outcomes.
- Attend and then consider applying to join your county mental health board/commission.
- Meet with your local mental health director and substance use administrator and ask what their plans are for integration and how they are going to ensure that the client and family member voices are included in all planning.

### Community organization

California put itself in the forefront of mental health system transformation with the Mental Health Services Act (MHSA). It’s a radical change, as is health care reform. The MHSA supported local client, family and community engagement in transforming the mental health system. **Many of the same basic and advanced community organization methods can be effective in supporting clients and family members to advocate for their own best interests in local planning for integration and health care reform.** Some key suggestions are listed below.

- Write Op-Ed and Letter(s) to the Editor about integration issues.

**Recommendation:** The *2009 Consumer Guide from the Patient-Centered Primary Care Collaborative* has as one of its four core elements “Tools for consumers and other stakeholders to assist with [Patient Centered Medical Home] PCMH education, engagement and partnerships.” The guide includes free, downloadable presentations and a long list of Tools and Resources. For more information go to <http://www.pcpcc.net/content/tools-resources-0>

- Speak at local clubs or churches about integration and health care issues in order to raise public awareness.
- Join and coordinate with other client and advocacy groups, e.g., NAMI, DBSA, MHA, and California Network of Mental Health Clients - to participate and stand together on critical issues.
- Recommend and work with your local MHSA committees to set up educational meetings for clients/family members and interested community members on topics such as the health risks faced by persons with MH and/or SUD, strategies for inclusion and improving health and wellness, health literacy, etc.
- Invite more parties to the table; the possibility of limited inclusion of clients and family members during the planning process concerns us. We feel it is important to add “new blood” to the process. Therefore, we recommend that clients and family members help to publicize meetings to organizations to which they belong as well as through announcements in the media, especially if the county is not publicizing meetings in the press, radio, and community cable channel.

## Effective communication

Because we’re all different, we’ll necessarily use a wide variety of communication styles. What is natural for one person may not work at all for another. And what feels natural may need to be modified somewhat in order to be effective, depending upon the person(s) with whom the speaker is communicating. Some of us are better at writing than at speaking. We encourage everyone to play to her/his strengths.

The following are some tips for effective communication when you engage in planning for improved health care.

Regardless of communication style, we do need to stand for our truth. Dr. Don Berwick, the director of the federal Centers for Medicare and Medicaid Services, is an outspoken advocate for client directed care as the “true north” in *Study to Action: A Strategic Plan for Transformation of Mental Health Care* (Adams and Daniels, 2011).

“... Using the metaphor of a compass, Berwick identifies the experience of individuals, families and communities as being ‘true north’ and central to any effort at quality reform. We must always orient our work to this ordinal point; it must always guide the way in systems change and improvement” (pgs. 18-19, Adams and Daniels).

- PATIENCE – remember, we’re moving from a top-down system with administrators and health care professionals in charge of patients (picture a triangle with flat bottom) to a client- and family member-driven system with clients AT LEAST sharing decisions with providers in determining treatment (picture a triangle with flat top where persons at top are the clients and their supporters).

Clients and family members may benefit by remembering that we are all in the midst of a major paradigm shift; it will most likely continue to change incrementally.

- GENTLE BUT PERSISTENT – One active mental health peer employee impressed us when she spoke about what works well for her:

“Learning how to work together with all communities politely and thoughtfully would take us a long way.”

Take the time to educate and listen to the other person’s perspective.

- ✓ Be gentle but persistent; be careful not to shout out your views.
- ✓ Model good character, working well together, being appreciative of each other’s skills and gifts, having hope for recovery.
- ✓ “Kill them with kindness” works well for some participants.
- BE COURAGEOUS – speak up politely and respectfully and not in anger.
- VOICE DISSENT – Sometimes effective change agents must express dissenting points of view. Walking on egg shells does not create change! If there’s an elephant in the room that everyone is ignoring, it takes guts to name it: “Look! There’s an elephant in the room. We have to deal with it!” When asserting a minority view, having one or more allies makes life easier for the dissenter and also increases the possibility that the dissenting opinion will be seriously considered.
- DEVELOP EFFECTIVE CROSS-CULTURAL COMMUNICATION SKILLS – local-level planning requires working with diverse communities. Becoming more aware of cultural differences, as well as exploring cultural similarities, can help you communicate with others more effectively. Next time you find yourself in a confusing situation, ask yourself how culture may be shaping your own reactions, and try to see the world from the other’s point of view.

## II. INTEGRATING MH/SUD AND HEALTH CARE AT THE PRACTICE LEVEL

There is a growing body of research and practice literature regarding how to effectively integrate MH/SU and primary care. The Milbank Report cited previously identifies models of integration. California counties and many agencies, including federally qualified health centers and mental health and substance

use service providers are taking steps to integrate care and are engaging in integration partnerships. However, it is beyond the scope of this paper to comment on the many evidenced-based and promising integration practices that are emerging. Rather, we will focus on the unique and important role that clients and family members can and should play as integrated services are designed and implemented.

Although we will not go into detail here, it is also critical that all staff – mental health and substance use services providers as well as primary care – be cross-trained about integrated care. Objectives of this cross-training include: developing basic awareness about the interaction of health and behavioral health conditions, risk screening and basic approaches to integrated treatment of MH/SUD/PC. Not only is cross-training important to provide effective care, cross-training helps all staff to better understand the wellness and recovery challenges that clients and family members experience due to providers’ lack of knowledge about client and family culture. This recommendation is crucial as local entities plan staffing of integrated care services.

In the rest of this section, we will discuss the contribution that peers and family members can bring to MH/SUD/PC integration as peer mentors, health navigators and promotores. We will also briefly discuss the rapidly emerging use of information technology as a vehicle for peer-to-peer information, support and education.

### Peer support

We strongly suggest that clients and family members who involve themselves with integration planning and implementation perform their own diligent research on how peers are used in their area and, ideally, to more broadly investigate how peers are contributing to recovery and integration in ways that may contribute to local planning. Then clients and family members will be well positioned to recommend ways for their county to include peers as providers in their integration plans.

On January 27, 2011, we presented an early draft of this paper at the California Mental Health and Sub-

stance Use Policy Forum: Building Collaborations for Health Care Reform. There was lively discussion regarding the role of peers in integrated health care services.

Peers can provide valuable support to individuals who are dealing with physical as well as mental health and substance use problems. Peers serve as role models and mentors.

We have ample evidence of the efficacy of peer self-help support in medical settings, for example, survivor-run support groups for persons with diabetes, heart disease, and cancer. However, there is only limited research regarding the efficacy of peers supporting individuals with co-occurring MH/SUD and medical conditions. This emerging research is promising and should be pursued.

Ben Druss, M.D., et al. investigated HARP (Health And Recovery Peer program) and concluded:

“This peer-led, medical self-management program was feasible and showed promise for improving a range of health outcomes among mental health consumers with chronic medical comorbidities. The HARP intervention may provide a vehicle for the mental health peer workforce to actively engage in efforts to reduce morbidity and mortality among mental health consumers” (Druss, et al., 2010).

A 2010 Carter Center 2010 report, *Pillars of Peer Support*, concluded that there is as of yet a very limited research “evidence base” for peers providing support in a medical settings, and identifies this expansion of the role of peers and family members as a service that should be explored with more research.

As we advocate and support the development of peer support models in integrated care, it is also important to understand that people who provide peer support need training and supervision. We need to learn more about whether mental health peers can effectively support other mental health clients regarding medical issues with which the peers have no shared experience. At a minimum, peers must be trained

to NOT give medical advice/tips without significant training and supervision about what is helpful and what may be beyond their knowledge and experience. This may be particularly important for clients and family members who are providing peer support to individuals with co-occurring conditions – mental health/substance use and medical care needs. It is also important, wherever possible, to “match” clients with peers who have lived experience with co-occurring mental health and physical health conditions. This matching allows the peer support staff with the similar lived experience and self-management knowledge to assist others with similar mental health, substance use, and physical health issues.

### **Peer/health navigators**

Peer navigators can provide critical support to clients and family members that experience difficulty in accessing services. Peer/health navigators can also provide community outreach and education in underserved communities and are effective as basic health advocates and educators. Promotores have been very successful in diverse ethnic, cultural and linguistic communities throughout California. Client-run agencies, including Project Return in Los Angeles, as well as programs in Contra Costa, Orange and San Mateo Counties, are actively exploring the use of mental health peers as health navigators and as leaders of self-management support groups.

### **Family as members of the support team**

Family members can play a critical support role and function as key members of a client’s care team. Family members are also increasingly employed in mental health systems as advocates and family partners. This is a role that should be further explored at a delivery system level as MH/SUD and primary care are integrated. The following are concrete suggestions about how family members can be effective in supporting their loved ones.

- ✓ Be present and attend appointments, meetings, whatever it takes to ensure the client’s information is accurately communicated to

all the care providers on a regular basis, and that families are included, if the client wishes.

- ✓ Insure that family members know how to navigate both mental health/primary care systems to support their loved ones who are clients/patients in each system.
  - ✓ Act as an integration leader through supporting family members/clients act as information communicators between mental health and primary care, thus facilitating integration of clinical/health information in compliance with HIPAA.
  - ✓ Advocate for system changes to ensure that family member involvement is encouraged and valued by staff in the integration of care for their loved ones.
  - ✓ Attend meetings and events to get to know the leaders and change agents that work in the local systems of care and to support their efforts to “change and integrate” health care at the local level.
  - ✓ Promote/market integrated care through education, resources, support groups, etc., that are happening, or promote the need for integration to happen in your county by working with NAMI, or other mental health and primary care advocacy organizations.
- *Facebook*: This social networking website can be used to connect and engage clients and family members in integrated care. Setting up a page within this website can allow those who use computers to make friends and receive up-to-date information about integrated care from the page owners.
  - *Computer Kiosks in Wellness Centers*: Computer kiosks can help clients and family members access needed self-management information in wellness centers and other places of integrated care. It is best to have clinical staff choose the URLs to place on the computer’s “favorite site” information bar as they will know if the information is authentic and evidence-based.
  - *Network of Care*: “...the Network of Care, recognized as a model program by the President’s New Freedom Commission on Mental Health, provides vital information to help link consumers to support groups and personal advocacy resources in the community. The site also provides a repository of evidence-based practices – successful, creative ways for communities to respond to their behavioral-health needs” (California Network of Care, 2011).

### **Information technology is creating new avenues for integration and whole health**

Information technology is rapidly changing how clients and family members learn about their health and mental health problems, share information and support each other. A recent February 2011 report from Pew Research Center, Peer-to-peer Healthcare, shows “...the extent of peer-to-peer help among people living with chronic conditions. One in four Internet users living with high blood pressure, diabetes, heart conditions, lung conditions, cancer, or some other chronic ailment (23%) say they have gone online to find others with similar health concerns...” (Pew Research Center, 2011).

The following are a few of the ways information technology is changing how we understand our health:

### **III. SELF ADVOCACY/SELF MANAGEMENT SUPPORT**

#### **Wellness recommendation**

Our overriding recommendation about wellness is that clients and family members familiarize themselves with the health and wellness concerns, potential for self-management alternatives and healthful practices of people with mental health, substance use disorders, and physical health problems. Armed with this information, clients and family members will be better positioned to recommend ways for their local community/county to include wellness programs in their integration plans.

It is increasingly well understood and accepted in the health care field that empowered, educated and engaged clients (and their families) are the essential agents in managing their chronic physical health

conditions as well as serious mental illness and substance use.

The following are some examples of self-advocacy and self-management support programs and tools:

**Recovery dialogues** occur in discussion groups intended to help participants build self-confidence.

- o Discussion groups that have as their major focus re-building a positive self-image and strengthening the belief in one's own abilities and potential for growth. This is done by enabling depth sharing in a safe environment in order for people to identify and reflect on those times in their lives when they were able to act on their own behalf and affect their lives in a positive manner.
- o Designed to help a person become aware that she or he can begin to take more control of one's life and increase his or her self-confidence.
- o Designed to cut across that belief that *'there is nothing I can do that is going to make my life better.'* This is done by enabling depth sharing in a safe environment in order for people to identify and reflect on those times in their lives when they were able to act on their own behalf and affect their lives in a positive manner.

(Appalachian Consulting Group, 2006)

**Wellness Recovery Action Planning (WRAP)** is a system for identifying your personal resources and using those resources to stay well. Comparisons were made of reports from 381 people before and after participating in WRAP education. Participants reported significant increases in: 1) their hopefulness for their own recovery; 2) awareness of their own early warning signs of decompensation; 3) use of wellness tools in their daily routine; 4) awareness of their own symptom triggers; 5) having a crisis plan in place; 6) having a plan for dealing with symptoms; 7) having a social support system; and 8) ability to take responsibility for their own wellness (Copeland, 2011).

**Pathways to Recovery (PTR)** a peer-led group was researched by a team at the University of Kansas who found "statistically significant improvements for PTR participants in self-esteem, self-efficacy, social sup-

port, spiritual well-being, and psychiatric symptoms" (U of Kansas, 2003).

**Dual Recovery Anonymous** is a chemical dependency – mental health hybrid, formed in 1989 out of a vision for both dual recovery and a fellowship to carry the message. DRA is a "fellowship of men and women who meet to support each other in our common recovery from no-fault illnesses: an emotional or psychiatric illness and chemical dependency..." (DRA, 2011). Its goal is to develop a self-help program for dual recovery based on:

- o Principles of the 12 Steps,
- o Personal experience of dual recovery,
- o Principles of personal freedom and choice.

**Peer to Peer, a NAMI course**, consists of nine two-hour units and is taught by a team of three trained "mentors" who are personally experienced at living well with mental illness. The mentors follow a script provided by NAMI and are paid a stipend for each course they teach (NAMI, 2011).

**Family to Family Education Program, A NAMI course**, is a free, 12-week course for family caregivers of individuals with severe mental illnesses.

- o The course is taught by trained family members,
- o All instruction and course materials are free to class participants,
- o More than 115,000 family members have graduated from this national program (NAMI, 2011).

**Facing Us Clubhouse** is an interesting, free and fun-to-use source of wellness resources. The website is described as an "Online Home for Wellness," published by the Depression and Bipolar Support Alliance. It offers a multitude of client tips, space to journal and tracks our moods and other resources "for anyone seeking inspiration and support for a life of health and well-being" (Facing Us Clubhouse, 2011).

**Peer Support Whole Health Training-PSWH (formerly known as Health and Recovery Peer (HARP) Program)** the previously mentioned program led by

paid mental health peer specialists in a clinical setting. This program was modeled on the work of Kate Lorig, M.D. and her associates at Stanford University Medical Center and adapted by Appalachian Consulting Group. Thus, PSWH is a mental health peer-led intervention to improve engagement and self-management for mental health clients with co-occurring chronic medical conditions (Appalachian Consulting Group, 2011).

**NAMI Hearts & Minds** from NAMI's education and support offers advice on medical self-advocacy, smoking cessation, substance abuse and alcoholism, healthy eating, exercise, and metabolic syndrome and Type 2 diabetes (NAMI, 2011).

**SAMHSA's 10X10 Wellness Campaign** mentioned in the Background Section of this paper has the goal to increase the life expectancy of mental health clients "by 10 years over the next 10 years." Their website contains wellness tools that California's local communities can use in their integration planning. As the SAMHSA website states,

"Wellness means overall well-being. It incorporates the mental, emotional, physical, occupational, intellectual, and spiritual aspects of a person's life. Each aspect of wellness can affect overall quality of life, so it is important to consider all aspects of health. This is especially important for people with mental health problems, because wellness directly relates to the quality and longevity of your life.

...The new focus on wellness highlights the importance of recovery from mental health problems. By pursuing wellness, we can reduce the disparity in early mortality for people with mental health problems, which is far greater than for any other population."

The 10x10 Wellness Campaign recently released free brochures and posters to support action to improve the life expectancy of people with behavioral health challenges (SAMHSA, 2011). An important free tool that we want to highlight is the *Eight Dimensions of Wellness poster* (on page 21).



# The Eight Dimensions of WELLNESS\*



Communication among mental health consumers, professionals, and primary care providers about health information is essential to overall wellness.



**THE 10X10 WELLNESS CAMPAIGN**

To promote wellness for people with mental illnesses by taking action to prevent and reduce early mortality by 10 years over the next 10 years. To find out more about the 10x10 Wellness Campaign, visit <http://www.10x10.samhsa.gov>.

**For information, contact:** SAMHSA 10x10 Wellness Campaign  
1 Choke Cherry Road, Room 2-1007  
Rockville, MD 20857  
10x10@samhsa.hhs.gov

\* Source: Swarbrick, M. (2006). A wellness approach. *Psychiatric Rehabilitation Journal*, 29,(4) 311- 3314.



### **Alternative wellness approaches**

The voices from our communities have also suggested alternative/additional methods and locations where integrated treatment might be made available. These suggestions come from a survey that was administered by the authors of the paper, the CalMEND Client and Family Member Integration Work Group.

#### **Wellness/health alternatives**

- Peer support, self-help, and wellness groups
- Yoga and tai chi classes, exercise groups
- Housing support programs and employment support
- Acupuncture, massage, sex therapy, non-medication sleep management, neuro-functionality testing
- WRAP training
- Physicals, women's health care and vision care
- Spiritual support groups
- Stress management groups
- Meditation groups
- Chiropractic care
- Native American talking circles and traditional methods/culture-specific ways
- Talk therapy support, as well as help for alcohol, drug and diet-related problems
- Nutrition, cooking classes
- Assistance to choose from a pool of doctors, etc.
- Recreation, art and music therapy in a group setting
- Mental health check-up with every medical appointment
- Groups and other assistance for smoking cessation

#### **Alternative locations for wellness activities and support**

- Schools
- Gyms
- Wellness centers
- Spiritual centers
- Churches, synagogues and other places of worship
- At job sites

# Section 4

## Voices from our community

### Introduction

We have discussed our perspectives and recommendations related to planning for integrated/whole health care in previous sections of this paper. However, it was also important to the Client and Family Member Integration Work Group to include broader stakeholder responses. To get the additional perspectives we developed a survey and obtained responses from clients, family members and providers about their experiences with integrated care including their perspectives on its benefits as well as concerns. This section describes the survey, its methodology, and highlights participant responses. Section 5 provides more detail regarding stakeholder responses.

### Survey method

The surveys on integration were developed on Zoomerang (an online survey tool) and distributed to clients, family members and providers, by membership organizations and government entities. These groups included:

- The California Network of Mental Health Clients
- National Alliance on Mental Illness
- County Behavioral Health/Mental Health Directors
- California Department of Alcohol and Drug Programs
- CalMEND Primary Care Integration Pilot Learning Collaborative counties
- Depression and Bipolar Support Alliance (DBSA)

Survey respondents were not selected on the basis of stratified or randomized selection methods and so cannot be considered representative of the range of perspectives on integration. However, this survey process has elicited perspectives and concerns that are important and bring life to the research that informs this paper.

NOTE: The percentages of respondents cited in each of the next sections exceed 100% due to multiple responses.

Diagrams 1,2,3 and 4 show respondent demographic information

Gender of the Client Respondents N=98		Gender of the Family Member Respondents N=27	
Female	42	Female	10
Male	36	Male	6
Unknown	20	Unknown	11

**Diagram 1**

Sexual Orientation of the Client Respondents N=98		Sexual Orientation of the Family Member Respondents N=27	
Heterosexual	51	Heterosexual	10
Homosexual	5	Bisexual	1
Bisexual	5	Unknown	16
Unknown	37		

**Diagram 2**

Ethnicity of the Client Respondents N=98		Ethnicity of the Family Member Respondents N=27	
Caucasian	70	Caucasian	6
African/African American	12	African/African American	4
Hispanic	10	Asian	2
Asian	3	Unknown	15
Unknown	3		

**Diagram 3**

<b>Provider Respondents</b> <b>Who do you serve?</b> <b>N=66</b>	
Persons:	
With SMI	62%
Whose SMI is stable	52%
With SUD/COD	87%
<p>(NOTE: The survey was not developed for providers of children’s services. Yet we were able to include many responses from providers of children’s services as we wanted to accommodate their request to complete and be included in our survey. You will see their answers below.)</p>	

**Diagram 4**

The survey has several parts. One part asks all survey participants to describe their experience with integrated care. For this, we used a level of integrated care typology described in the Milbank Report, titled, “Evolving Models of Behavioral Health Integration in Primary Care” (May 2010). The Milbank typology is shown on page 25 as Diagram 5.

**Definition of types of integrated care: Check those that most closely fit for you.**

- Minimal collaboration: Mental health providers and primary care providers work in separate facilities, have separate systems, and communicate sporadically.
- Basic collaboration at a distance: Primary care and behavioral health providers have separate systems at separate sites, but engage in periodic communication about shared patients/clients.
- Basic collaboration on-site: Mental health and primary care professionals have separate systems but share the same facility. Proximity allows for more communication, but each provider remains in his or her own professional culture.
- Close collaboration in a partly integrated system: Mental health professionals and primary care providers share the same facility and have some systems in common, such as scheduling appointments or medical records. Physical proximity allows for regular face-to-face communication and there is a sense of being part of a larger team treating shared patients/clients.
- Close collaboration in a fully integrated system: The mental health provider and primary care providers are part of the same team.
  1. Mental health or substance use services are provided in primary care (The client/patient receives mental health or substance use treatment as part of his or her regular primary care) or
  2. Primary care services are provided in a mental health or substance use clinic (The client receives basic primary care services within mental health or substance use disorders program. The program may be dual certified as a mental health and primary care clinic.)
- None of the above: If you provide integrated services that don't fit with the above, please briefly describe \_\_\_\_\_

**Diagram 5:** Evolving Models of Behavioral Health Integration in Primary Care – 2010 (pgs. 13-15, Collins, Hewson, Munger, and Wade)

### Responses within the context of Milbank's Integrated Care Typology

#### Clients' experience of integration

Using Milbank's typology as a framework, 44% of the respondents felt they received minimally integrated care. The percentage of respondents who chose the

other levels of Milbank's typology included: 22% close collaboration in a fully integrated system, 15% close collaboration in a partly integrated system, 14% who have none of the types, 12% who have basic collaboration at a distance, and 11% with basic collaboration onsite.

### Family member experience of integration

Again, using Milbank's typology, 55% of the respondents felt their family members received minimal collaboration. The percentage of respondents who chose the other levels of Milbank's typology were as follows: 32% indicated basic collaboration at a distance, 18% selected "none of the above," 9% indicated basic collaboration onsite and close collaboration in a partly integrated system and, finally, 5% stated that they experience close collaboration in a fully integrated system.

### Provider integration experience

We also solicited information from providers about their participation in providing integrated care. Using the Milbank Report typology, 38% the respondents felt that the integrated care type they provided was basic collaboration at a distance. Provider respondents reported participation in the other levels of the typology as follows: 24% of the respondents felt they provided minimal collaboration, 14% provided close collaboration in a partly integrated system, and 11% provided basic collaboration onsite, close collaboration in a fully integrated system, and "none of the above."

### Has a consensus been reached?

#### Clients

Some client respondents provided a range of responses to survey questions about how integrated care is working for them: "**Perfectly,**" "**It's not,**" and "**I don't receive integrated care.**" Those respondents who do not receive integrated care expressed an interest in receiving it with comments including:

"**When will it be available?**" and "**Integrated care is the best way to help most people.**" The survey answers tend to support integrated care as a possible client choice.

#### Family members

Overall, family members indicated a preference for integrated care. The survey shows that more coordination is needed between behavioral health and physical health. The respondents stated integrated care works best. One respondent stated they would "**like mental health, substance use and primary care providers all in one location.**"

#### Providers

With the implementation of the 1115 b Medicaid Waiver and health care reform, overall, the data shows that 59% of the provider respondents are planning to expand or increase the availability of integrated care. One respondent stated, "**Co-location of primary care and mental/substance use services would be a huge help.**"

The Client and Family Member Integration Work Group of CalMEND did not draw any firm conclusions from this limited survey data. However, we have identified a general preference among respondents for integrated mental health/substance use and primary health care, and we strongly recommend that clients and family members become involved in local level integration planning.

The second part of the survey, which is Section 5 of this paper, outlines respondent's recommendations for participation in the planning and provision of integrated care.

# Section 5

## Stakeholders' recommendations for client and family member involvement in local Integration planning

The health care system and clients and family members who need to access services are caught up in the rapid pace of change related to health care reform including the implementation of the CA 1115 b Medicaid Waiver and the Federal Affordable Care Act (ACA). Both the California Medicaid Waiver and the ACA promote coordination and integration of care-- among primary and specialty care including mental health and substance use services. We will highlight a few recommendations in this section that underscore the importance of “Nothing About Us, Without Us.”

### Client responses

Client responses indicate that 73% are not involved in planning for health care reform in their county.

Some respondents felt that their families were more important than being at the planning table for integrated care. Others felt that clients at the planning table were important. And finally, respondents felt education about system planning and changes is important.

Those who felt involvement was important suggested the following actions: communicating with local newspaper, cable TV and radio; speaking up; developing information dialogue sessions and joining client and family member advocacy groups. The benefits of involving clients are clearly stated by one respondent: “You can’t get better information [than] from clients and family members since they live the experiences every day.”

### Family member responses

The survey data shows that 52% of the respondents are not involved in planning for health care reform and 48% state they are involved in some way.

Family members responded that clients and family members should be asked to join the planning process. It is important to be respectful and listen to family

member concerns. How? Use open meetings and joining and/or collaborating with family advocacy groups are tools to involve clients and family members. One respondent stated that, “Clients and family members are most aware of what is needed for them.” One response clearly supports the recommendations stated in this paper, “**Provide more holistic care; treat the whole person not just a piece.**”

### Provider responses

Most providers responded that clients and family members are not involved in planning for health care reform in their county.

In Los Angeles County, a CEED participant, stated, “Currently we have identified clients who may qualify but family members have yet to participate” and “Clients have been identified for the 1115 Waiver but families are yet to be determined. The process recently began at this clinic.”

Providers made numerous recommendations about how clients and family members might become more involved. They suggested outreach, administering questionnaires, joining advocacy group’s discussions, partnering with community leaders, and holding stakeholder meetings in the community. The use of TV and radio spots was suggested as well as holding gatherings at community, church and sports events.

The provider respondents were very clear that “we’d have better plans” by having clients and family members at the table during planning for integrated care and health care reform.

Provider respondents also acknowledged that un- and under-served cultural groups are not well represented in planning for health care reform and/or integration of care. Fifty three percent of providers state that cultural groups are not involved in planning for health care reform. Some comments included:

- It is not clear how these groups are involved at the county level.
- Cultural groups need to be invited or accessed through their own communities: such as cultural events, cultural centers, place of worship or places they gather. Information passed through media, radio, in front of ethnic markets, newspaper, and advertisement in public transportation as to inviting them to be involved in their language to ensure everyone is aware of the health care reform in counties.

## Conclusions

We want to thank everyone who completed the integration survey. Clients, family members, and providers believe that integrated care and person-centered health care homes offer hope for better total health for persons with MH/SUD and physical health care conditions. There are exciting models for integrated care that are emerging and evolving at the local, state, and national levels. In this paper we have opted to focus on the values and beliefs underlying integration models rather than to recommend any specific current operating models. We have, clearly stated our

position that integrated public health care is necessary to combat the unconscionable disparities in morbidity and mortality rates experienced by people with SMI, SUD and COD. And, the stakeholder survey clearly supports our position.

We end this paper with a hope that the issues, values, and tools that we have described will promote greater shared understanding and empowerment as California moves forward with implementing the California 1115 b Medicaid Waiver and the Affordable Care Act, i.e., health care reform. And, again, we must state: NOTHING ABOUT US WITHOUT US as we move forward together to support wellness and recovery for individuals with behavioral and physical health challenges.

## Online learning

SAMHSA and the University of California, Davis, School of Medicine have provided valuable online resources that can be viewed anytime. The webinars shown on the following pages focus on health care reform, the person-centered health home, and cultural competence.

## SAMHSA YouTube Channel

### Health Care Reform: Implications for Behavioral Health Providers

"The passage of the Affordable Care Act (ACA) has ensured that the role of behavioral health in the overall health care system will change. Now, it is more important than ever to know how health care reform will affect you and your role and the role of states, behavioral health care providers, and consumers. Due to the breadth of the new law, ACA sets forth concepts that are new to many individuals and families that currently or will receive mental health and addiction services. Recognizing the importance of understanding these new concepts, SAMHSA is hosting a fall webinar series.

This webinar covered how health care reform will affect the role of states, behavioral health providers and consumers; what is considered a health home; what services are provided in a health home setting; and which states are currently using health homes. Evidence-based approaches for people with co-occurring disorders and the role accountable care organizations will play was also discussed."

Click on the blue underlined title and you will go to the SAMHSA YouTube Channel in order to view the video there.



Or

Click on this link to view the video  
[http://www.youtube.com/user/SAMHSA#p/u/37/D0z1T3CRh\\_8](http://www.youtube.com/user/SAMHSA#p/u/37/D0z1T3CRh_8)

## SAMHSA YouTube Channel

### [Webinar: Integrating Behavioral Health into the Person-Centered Healthcare Home](#)

"This 90-minute webinar covered the topic of behavioral health as a key component of medical home service delivery. This webinar provided concrete examples of how and where to best serve people with behavioral health disorders in the medical home continuum. Bi-directional integration came alive as the panelists shared their accounts of their efforts to embrace integration.

The presenters were experts in the following behavioral health settings 1) primary care setting integration with behavioral health services; 2) behavioral health setting integration with primary care services; 3) behavioral health setting integration with private primary care practitioners; 4) and behavioral health setting becoming a federal qualified health center offering integrated services. These presenters spoke of their experiences and address issues such as their organizations' readiness for change, the process of integration, opportunities that have come with integration and challenges they have faced."

Click on the blue underlined title and you will go to the SAMHSA YouTube Channel in order to view the video there.



Or

Click on this link to view the video  
<http://www.youtube.com/user/SAMHSA#p/u/27/-jZG1AP6-zA>

## UC Davis YouTube

### Webinar: "Cultural Competence and Quality of Care"

"Explore the concepts of cultural and linguistic competency in delivery of health care services and in health care workforce development. Dr. Sergio Aguilar-Gaxiola, of the UC Davis Center for Reducing Health Disparities, presents an outline for a culturally proficient health care system. Series: "UC Grand Rounds Series"

Click on the blue underlined title and you will go to the UC Davis YouTube in order to view the video there.



Or  
Click on this link to view the video  
<http://www.youtube.com/watch?v=gH0ynwoZgJU&feature=youtu.be>

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**Integration Now and During Its Evolution**  
*Embracing our Values from a Client and Family Member Perspective*

2011



"Other's Point of View"

### Cover Graphic

What does the cover mean? The cover is a typographic design. The words and phrases were assembled from the surveys that were sent to clients, family members, and providers.

The words, "clients, family members, and providers" are in no particular order except they arbitrarily follow the number of respondents. There is no hierarchy implied, unless you say that family members are a foundation and clients sit at the top, which is 'true north.' Clients and family members surround providers as we implement integrated care, the California 1115 b Waiver, and the Affordable Care Act.

It is clear though that most of the words and phrases are located next to the stakeholders who said them. There are two exceptions: "Building Realities..." was written by a provider and "...a valuable resource" was written by a client.

The designer wanted to convey the entire message of the paper which was very congruent with the three survey's answers. The message is stated well on the cover.

Thanks to the subcommittee and advisors for their support in creating a consensus graphic for the cover.

Alice J. Washington

Graphic Designer



California Institute for Mental Health  
2125 19th Street, 2nd Floor  
Sacramento, CA 95818  
(916) 556-3480 • [www.cimh.org](http://www.cimh.org)