Integration of Mental Health, Substance Use, and Primary Care Services
Embracing our Values from a Client and Family Member Perspective

2011

Volume 2
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

This clients and family member issue paper was developed by the Client/Family Member Sub-Committee of CalMEND through the support of CiMH. CalMEND is a program of the California Department of Health Care Services (DHCS) in partnership with the California Department of Mental Health with funding support provided through the Mental Health Services Act. CiMH supports the Client and Family Member Sub-committee and other core CalMEND project initiatives through a contract with DHCS. Click on www.calmend.org for more information.
Voices from our Community

A brief overview of the Zoomerang answers from an external survey that was not random and not stratified. We solicited responses to integration of care. The respondents were clients, family members, and providers.

CalMEND Client and Family Member Integration Work Group
Integration of Mental Health, Substance Use, and Primary Care Services
Embracing our Values from a Client and Family Member Perspective
2011
Section 1
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. The last section 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

<table>
<thead>
<tr>
<th>Gender of the Client Respondents N=98</th>
<th>Gender of the Family Member Respondents N=27</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female 42</td>
<td>Female 10</td>
</tr>
<tr>
<td>Male 36</td>
<td>Male 6</td>
</tr>
<tr>
<td>Unknown 20</td>
<td>Unknown 11</td>
</tr>
</tbody>
</table>

Diagram 1

<table>
<thead>
<tr>
<th>Sexual Orientation of the Client Respondents N=98</th>
<th>Sexual Orientation of the Family Member Respondents N=27</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heterosexual 51</td>
<td>Heterosexual 10</td>
</tr>
<tr>
<td>Homosexual 5</td>
<td>Bisexual 1</td>
</tr>
<tr>
<td>Bisexual 5</td>
<td>Unknown 16</td>
</tr>
<tr>
<td>Unknown 37</td>
<td></td>
</tr>
</tbody>
</table>

Diagram 2

<table>
<thead>
<tr>
<th>Ethnicity of the Client Respondents N=98</th>
<th>Ethnicity of the Family Member Respondents N=27</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian 70</td>
<td>Caucasian 6</td>
</tr>
<tr>
<td>African/African American 12</td>
<td>African/African American 4</td>
</tr>
<tr>
<td>Hispanic 10</td>
<td>Asian 2</td>
</tr>
<tr>
<td>Asian 3</td>
<td>Unknown 15</td>
</tr>
<tr>
<td>Unknown 3</td>
<td></td>
</tr>
</tbody>
</table>

Diagram 3
Provider Respondents
Who do you serve?
N=66

<table>
<thead>
<tr>
<th>Persons:</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>With SMI</td>
<td>62%</td>
</tr>
<tr>
<td>Whose SMI is stable</td>
<td>52%</td>
</tr>
<tr>
<td>With SUD/COD</td>
<td>87%</td>
</tr>
</tbody>
</table>

(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.)

Diagram 4
Client Responses

1. **Who is providing your mental health care?**

   Of the client respondents, 67% stated that psychiatrists provide their mental health care, and 21% of clients stated their mental health care is provided by psychologists and primary care.

2. **When you hear the word recovery, what do you think of?**

<table>
<thead>
<tr>
<th>Recovery Topic</th>
<th>Percentage of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recovering from mental health issues</td>
<td>80%</td>
</tr>
<tr>
<td>Recovering from physical health issues</td>
<td>48%</td>
</tr>
<tr>
<td>Recovering from substance use/abuse issues</td>
<td>71%</td>
</tr>
</tbody>
</table>

3. **How would you define the word recovery as it pertains to you as a whole person?**

   • Getting well or better
   • Recovery is taking daily steps that support my physical, mental, spiritual, emotional and/or social well-being.
   • To restore 80% of my previous best: Function, energy, stamina, sexual interests, aerobic fitness, income, etc.
   • Getting to know yourself again, your strengths and weaknesses, your limits and boundaries, being healthy physically, emotionally and mentally/spiritually
   • Being able to do the things that I love; I get to define those things (and redefine them too) and they may pertain to work, school, and fun, social life, family life and sometimes just vegging out!
   • Recovery - to me means getting better as well as physically, spiritually. Also, A Healed Soul.

   **Substance Use**

   • Stay clean and stable
   • Mental and substance relief
   • Recovery is an opportunity to pause and reestablish my relationship with God and a healthier lifestyle; substance-free lifestyle
• Able to live a meaningful life without drugs or alcohol or other substance abuse to self-medicate and self-supporting

• I don't think of myself in recovery but I no longer use drugs/alcohol so I guess by definition that's recovery.

4. Are you concerned that the wellness and recovery vision which has been expanded in MH with the Mental Health Services Act would be lost with the integration of mental health, substance use, and primary care?

Almost half of the respondents (53%) said “No” they are not concerned that the wellness and recovery vision will be lost with integrated care, and 47% say “Yes”. We are highlighting very real concerns around the last answers.

• Very concerned. We must keep the positive, preventative, self-determined wellness focus through this transition! Integration should be the opportunity to strengthen this focus by building on the mutual relationship between physical and emotional health.
• Yes, mental health is like the ugly step child of the medical model paradigm
• I think that we would need to re-educate the entire medical community about wellness and recovery for people with mental health issues.
• All these years we have asked for holistic health—mind, spirit and body. Now that it could be possible all the gains we have made in becoming part of the policy-making and decision-making will be pushed aside, because primary care thinks of us as patients not partners
• I only say yes here because it seems as if the Primary Care providers are leading the discussion without the mental health care providers. They as far as I know are not familiar with recovery or the vision of MHSA
• We hear little mention of mental health in the health care debates...we are being forgotten, shunned, shamed...again!

Substance Use

• Many people in the MH Systems believe that recovery in MH is the same as substance abuse recovery, it is NOT!!

5. What recovery-oriented services would you like to have available from primary care?
(Peer support, self-help-, alternative therapies, housing, employment, etc.)

• Self-help, alternative therapies (very important)
• Peer support, self-help, and wellness groups, yoga and tai chi classes, Capacitar classes, exercise groups, access to acupuncture and massage, housing support programs and employment support
• Acupuncture, massage, sec therapy, non-medication sleep management, neuro-functionality testing, etc.
• Peer supports, self-help, WRAP training, housing
• Physicals, women’s health care and vision care
• Peer support, self-help, employment
• School

• Awareness on where to find groups on empowerment, self-esteem, cognitive behavioral change, WRAP, DBT, individual and group therapy; Peer-to-Peer sharing; An arena to get out the positive changes and progress that has and is happening with those diagnosed with mental health issues. Work to diminish the stigma that surrounds mental health.
• All primary care must include peer services, mentors, and navigators as a minimum. Housing and employment are best left to specialists, but primary care should be knowledgeable about how to access them and make them available. While primary care may not offer alternative therapies, they should be open to the discussion by a client, and assist in obtaining the request if there is no possible harm.

*Cultural Competence*

• More cultural awareness groups

6. **What do you find positive about your integrated care?**

• My care isn't integrated at all.
• I don't have it

• No integrated care
• I don't receive integrated care.
• Would only have to go to one place for all services

• Easier to come to one place for all services
• Still in planning stage
• We are just now putting the fully integrated system in place, so I have no reference on experience to base an answer on.
• Everyone working as one helps continuity of care
• The client does most of the integrating. Helps address greater range of issues, efficiently.
• Access, convenience, easier for patient

• Weekly/biweekly communication
• Knowing that I have a counselor that works with me on my emotional/mental issues in conjunction with my primary care physician and my health/physical issues is a very positive approach to my overall care

• Everybody knows me and they communicate among themselves so I don't have to keep track of all that is happening

• Both my psychiatrist and Internist can keep in contact via phone and online.

• My bills are paid, I get doctor visits with my psychiatrist, my primary doctor and my psychiatrist talk, my case manager helps me take care of business, I participate in groups at the Wellness Center to better myself.
• I direct my self-care and have an open honest partnership with my PCP.

Substance Use

• COD group

7. How is integrated care working for you?

• Perfectly, fine, good, very good, great, well, very well, and working well (at least 21 instances of these responses)
• It has proved invaluable to me when I am advocating for change.
• I like the services. I like my nurse practitioner.

• The doctor here cares a lot for my mental health
• AWESOME! It really helps to feel like I am taken care of and taking care of myself from head to toe. With the side-effects of the meds it is crucial for my primary doc and the dentist to be involved and knowledgeable

• My Internal Medicine doctor does not know a darn thing about mental health issue. She says all she can do is to prescribe mild tranquilizers for nerves...

Cultural Competence

• Integrated care is working for me because I can be able to focus more on what the clients are needing the most. I like working with the underserved populations like the LGBTQI and TAY the most. For me, it is like the next generation of mental health care advocates. I like to see into the future and wait to see how it going to be in 20 years or so.
- Not working. Medical model is too generic, too shallow. Doesn't integrate spirituality, art, music, human relationship

8. Are there any concerns that you have about integrated care?

- I would prefer to have integrated care. However at this time I have excellent PC and BH providers. They have each other's contact information. I would not want to sacrifice the high quality of care for mediocre or worse integrated care. As a poor person, I do consider myself very fortunate to have such good providers, all of whom accept Medi-Medi. My psychiatrist at UC Davis Sac is specialist in bipolar and always replies to my e-mails very quickly. The one or two times I've phoned in the several years he's served me, he has returned calls the same day.
- Could limit provider choice; all the other concerns are minor to the benefits
- I worry that my primary care provider could be choosing my psychiatrist
- I may be concerned that decisions would be made without enough input from me. I am struggling right now with what insurance thinks I need vs. what the doctor prescribes
- That the clients won't have any say in their treatment and there will be too many changes which will discourage clients from going to appointments and groups
- I think it is possible that if a person does not have the right person on the team – providers with whom a relationship can be developed trust goes down the tubes and information sharing becomes very difficult due to the lack of trust.
- I am concerned that my health might get short changed.

9. Do you receive any wellness-oriented services that support integrated care?

   Again, the data is almost split in half, with 52% saying “No” they do not receive wellness-oriented services that support integrated care and 48% saying “Yes”.

   - Acupuncture, yoga, spiritual support groups-none are part of my healthcare services. I seek these out independently.
   - Support Groups, self-care, WRAP, etc.
   - Orange County: MHSA: Wellness Center
   - Stress management group, meditation group at the Wellness Center in the community (EPA)
   - Chiropractic Care
   - Peer Support
   - Spirit Center

   Substance Use

   - Attends AA meetings in the community
• Attends COC groups and other self-help groups offered in the Wellness Center...Have talked about integrated service in COD group

10. Do you have any recommendations about how to bring wellness and recovery to integrated care? What might that look like?

Of the client respondents, 59% had recommendations as to how wellness and recovery might be brought into integrated care.

• Continue to build the workforce using people in recovery as peer providers. Use consumers and family members in primary/integrated care settings as navigators and support group/wellness education programs to supplement and reduce reliance on medical care.
• It would be nice to have a system in which a participant could receive help w/everything from housing, physical, mental health, dentistry, employment, all in one place.
• Educate, educate—train—demonstrate. Have client assist in preparing the next generation of service providers in all disciples. We would be part of the academic team at high schools and colleges. Students/existing staff would attend trainings throughout the year. Peers would be respected members of every staff and at every level.
• Assure that health services has topical self-help groups such as diabetes etc. and cross train health providers with available mental health self-help groups—ex. situation—my daughter weighed 180 when she was put on one of the new atypical which caused substantial weight gain during the year following she gained 130 pounds and no one in either the MH or general or special medicine physicians she saw during that time on a monthly basis said boo! About it—that is a crime.
• First you would need something besides medical model of car. In my county they have something that they call a Wellness Center. It is rally nothing more than a MH clinic with a big waiting room where clients are incurred to talk to psych interns and psychiatrist prescribing meds. There is a smile room on one side that has self-help groups two or three times a week. They have it all backwards what is needed is Holistic Center where real recovery orientated services are stressed.
• What is needed is a Holistic Center, grassroots model where real recovery orientated services are stressed and consumers formulate policy and administration.
• It would look like everything in one place psychiatry, primary, substance, peer help under one building thereby being real Public Health
• One-stop shopping

Substance Use

• Need to have more staff that are understanding of the addicted person without being judgmental

Cultural Competence
• Using people from the community, who know the community well, real peers from the community, with same ethnic and cultural background

• Using Peer Bridger to connect the various segmented systems - something like Promotores in the Latino culture.

11. Do you have any concerns about sharing confidential mental health and/or substance use information with primary care providers?

The majority of client respondents (72%) stated, “No”. We also highlighted one “Yes” answer.

• YES, STIGMA IS VERY STRONG IN THE PRIMARY CARE COMMUNITY
Family Member’s Responses

1. Please tell us a bit more about what type of integrated care your family member is receiving.

- No integrated care. Primary doctor and drug treatment provider aren’t even communicating.
- None...has Medicare and Blue Shield, we can’t get them to pay for his care as they are always fighting as to whom is responsible...constantly appealing.
- None, no one talks to each other. Especially when one case manager transfers to another...
- It is not integrated.

- Primary care is aware of mental health treatment, but not closely involved in any treatment decisions.
- Psychiatrists do recommend checking on the physical problems which may be associated with patient’s anti-psychotic meds
- The addiction rehab includes the groups, the multi-family groups, case management. That team referred him to psychiatrist to manage medication related to addiction. Separately, he is seeing psychologist for mental health therapy.

- The integrated care depends on the situation and the willingness of the principals to include the family member in the conversation.

2. What do you find positive or helpful about the integrated care for your family member?

- Would help if it happened
- Don’t have it
- Not at all
- There is not much coordination at this time.
- Doesn’t exist, family doctor doesn’t want to deal with medication cocktails. Have to use a psychiatrist for medication, psychologist for counseling as they understand the developmental disability, TBI, and bi-polar along with agnosagnasia better than the MD
- If it were to happen, I think the fact that our goals and treatment and medication and therapy and AOD services were aligned would be a great help to the consumer and family

- It is working out great. My family member is doing well.
- The support group helps me to understand what both are experiencing and that I am not along. I also get ideas for how to respond to them.
3. Are you concerned that the wellness and recovery vision which has been expanded in MH with the Mental Health Services Act would be lost with the integration of mental health, substance use, and primary care?

The survey data shows an overwhelming 74% of family members do not believe the wellness and recovery vision will be lost with integrated care. Specific comments from 26% of the respondents who felt the vision would be lost stated:

- More afraid that substance use treatment focus will be lost or diminished
- Not if integrated properly. I would hope that the results would be far superior if the person is treated as a whole person with many parts
- I am concerned only that the vision will be lost if funding is lost.

4. What recovery-oriented services would you like to have available from primary care for you and your ill family member?

- Native American Talking Circles and traditional methods/cultural specific ways
- Talk therapy support, as well as help for alcohol, drug and diet related problems
- Yoga, Tai-chi, gym, nutrition, cooking, ability to choose from a pool of doctors, etc., and services that are not just in the ‘poor’ areas of town
- Recreation, art and music therapy in a group setting offered on Sunday afternoons
- Mental health check-up with every medical appointment
- Client supported...more counseling
- Support for medications and jobs
- Better engagement for her with the services that are available such as smoking cessation, nutrition information, exercise programs
Provider Responses

1. Are you planning to expand or increase the availability of integrated mental health/substance use/primary care services in your agency or county? If yes, please describe briefly.

The data shows that 59% of the respondents are planning to expand or increase the availability of integrated care.

Their comments include:

- We are planning to do this; however, we are not yet clear on how this may be implemented. There seem to be too many unknowns at this point.
- We would love to work more closely in collaborative settings; if budgets would allow it.
- Our agency would like to provide an integrated care model in order to better address physical and substance abuse needs as well as we do mental health needs.

- We are adding eligible Medi-Cal eligible persons to our health care services, as defined by the Medi-Cal Waiver.
- The county has opened an Integrated Behavioral Health clinic.
- Our program is expanding our hours and number of employees providing services.

- We are in the process of opening a community health clinic.

- We are strengthening relationships with PCP and also we are bringing in PCP to our facilities to see clients when possible.
- We currently have an RN on-site full-time to address the physical health needs of our mental health clients. We also have a nutritionist on-site.

Responses from Children Providers

- We have instituted an internship program for MFT interns. We also have hired a licensed therapist for our children’s department.

2. Are client and family members involved in planning and shaping the design and overall delivery of your services?

Overall, 74% of the respondents affirmed that client and family members are involved in planning and shaping the design and overall delivery of services.

- Not as far as I know.
• Yes, the client determines what wellness means to her/him and is supported by family members.
• We have a family night so that family members can receive training on addiction. The families gain greater understanding on recovery and how to build healthy relationships with each other.
• The Mental Health Division includes peers in planning, service delivery, and evaluation of mental health services.
• Clients drive their service plans. Families are involved when we can obtain consent. Family members and clients hold regular jobs here to assure we have that perspective at the table. We also have client and family Advisory Boards.
• NAMI members are invited and consulted; the Mental Health Advisory Board has community members, including consumers. All county programs have consumer boards which meet at least monthly.

Responses from Children Providers

• Our agency employs parents of special needs children at all levels of management with full involvement in policy and program decisions.
• Family members are directly involved in creation of treatment plans and are encouraged to attend family support groups.

3. Are cultural groups that are UN/underserved involved in planning and shaping the design and overall delivery of your services?

63% responded that cultural groups are involved in planning and shaping the design and overall delivery of services.

• Not as far as I know.
• I don't think so - probably not.

• In every step of the way and services are delivered in the client's own language.

• We invite peers from diverse communities to take part in our planning and other processes.
• Yes, outreach through paraprofessionals and professionals of the selected underserved culture reach out to community and give talks to interdisciplinary staff working in the hospital.
• The majority of our clients are underserved or minority groups. They provide us feedback via surveys and in person about what things we are doing well and what we can do better.
• Our county believes in cultural competent services. A lot of time is spent on training, focus groups, hiring staff of all cultures to have a voice in the system.
EMQ Families First has a comprehensive Cultural competency Plan that ensures full involvement of representatives of the communities we serve in our program designs and CQI process.

Many/most of our child clients who are being adopted from the foster care system belong to underserved groups and we pay specific attention to issues related to transitional adoption.

4. Are individuals who have experience as clients/patients and/or family members now included in integrated service delivery in your program(s)? (Examples: Wellness Coaches, Patient Navigators, Educators, Wellness Group Facilitators, etc...).

67% of the provider’s respondents stated the individuals with experience as clients/patients and/or family members are included in integrated service delivery.

- This occurs more in our mental health programs where current consumers assist staff. Substance use disorder treatment programs have had little success in this; some staff is former consumers, however.
- Yes. Clients are incorporated as mentors.
- We have an alumni group that returns after completing the program to interact with the current residents so that they have a framework of what life is like after treatment.
- Peer Counselors and Support Group Facilitators
- Our program utilizes peer specialists (those who have past experience with mental illness and substance abuse) as an integral part of our team.
- Currently, we have Peer Advocates that assist other clients. They go through a training process and in the end are capable of facilitating groups.

- We have navigators in our older adult program assisting clients, peer advocates working in our orientation group.
- Clients have the option to include family and interested parties in their treatment.

We have a parent partner.

Yes, as family partners, patient advocates, and lay support personnel.

80% of our services have full time, employed parents of special needs children entitled; Family Partners

We have parent mentors who are adoptive parents who have previously utilized our services.

Responses from Children Providers
• They become mentors for other families who are experiencing similar situations. They may also present at our preparation classes for families prior to receiving mental health treatment for their children.

5. What have your successes been with involving clients and family members in integrated service delivery planning?

• We have a small alumni group that is successful bringing their experiences to us. This information helps us prepare our current clients.
• Families who attend family night have a greater involvement in the resident’s recovery.
• The Peer counseling program in Nevada County, California started with a handful of clients and one Mental staff (me) in 1997. A non-profit organization was formed and the Empowerment Center was opened in 2004--it continues to provide services today. I have been retired for three years now and the Center has continued on. The Peer Counselors and the program has its ups and down, but they are very committed to continuing to provide services.
• Good success at getting consumers to come to monthly meetings and give input, especially when lunch provided.
• Personally, I have 2 clients who demonstrated the capability of becoming Peer Advocates. They both have started the program and are looking towards completing. This would not have been possible if for not the participation of the family.

Responses from Children Providers

• Excellent when we can arrange it. Necessary for parents with children and success with kids depends on involvement with parents.
• We are so much more effective with engagement and re-engagement with Family Partners leading the way. They have taught us about sensitivities and approaches that we were unaware of and they give voice to those families who have lost theirs.
• Success involve being able to serve all aspects of mental health including education, psychiatry, psychology, medicine. We work with children and families. Multiple informants and providers have been a barrier to treatment for this population, but with integrated care we can provide superior treatment.

6. What challenges have you experienced in involving client and family members in planning for the overall delivery of services?

• It is a bit of work getting people to the table. And it is a balancing act as we prioritize the client’s individual treatment.
• Having family members really show respect to the peers/clients for their opinions, ideas, education, experience. The I/we know what is best for you attitude needs to go. All service delivery persons, peer/clients and family members need to have equal power.
• Money and time - This is very labor intensive and we don't have the people or the money to do.
• Dishonesty and lack of Insight and/or Openness to suggestions
• They aren't willing to really support the client; they are there to have you 'fix' the client to be less of a burden on the family.
• Level of interest seems low at times.
• Bringing in bread-winner members of the family (usually men), accommodating their work schedules and transportation barriers
• It is sometimes difficult to get family members to participate in services, especially when working against cultural biases and stigma still associated with SMI.
• When families are burnt out or when clients refuse family involvement.

7. Do you have ideas/recommendation for how these challenges could be addressed?

• Continued education
• Training and support for providers, consumers, and family members. Client sensitivity training for staff to reduce stigma and inform them of consumer and family member values and community issues, as well as information about recovery.
• Mental health services must be included in health insurance plans.
• I think the hardest challenge is getting Primary Care to help us (BHS) with our clients, no matter the severity. Cost of meds and formulary limitations is often a huge issue. PCP's feel untrained and unable to treat our very ill patients. Co-locating psychiatrists or psychiatric nurse practitioners in PCP clinics would be a great help.
Section 2

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

1. Are you or clients and family members involved in planning for healthcare reform in your county?

The respondents of the client survey show that 73% are not involved in planning for healthcare reform in their county.

2. If yes, what kinds of involvement do clients and family members have?

- My county is probably not even aware of the changes coming, let alone asking for the community or stakeholders to participate in the planning
- Some are involved in healthcare reform at the DPH level, some of us are involved at the MHSA level, others clients are involved at the SB or MH level. Got it covered
- We are working 25% of time on reform. 75% of time and effort on revolution. The revolution comes by understanding and promoting the MHSA.
- We are awaiting the role out on the health care reform and seeing what is going to be done with it in Sonoma County. We are anticipating either more services or more financial backing with the health care reform in the future.
- We are invited to the table for planning.
- Extensive meetings with community mental health services and NAMI members
- The involvement I have is with the California Network of Mental Health Clients. We are looking at the peer run programs and attempting to find ways for them to be brought in as a continuum of care under the new reform. No clinical input only peer assistance.
3. **What are your recommendations for how clients and family members might be involved/more involved?**

- It's up to them if they want to get involved. My family doesn't want to get involved.
- Client stated that he might possibly want certain family members involved in his treatment
- I do not know how to approach my family with these issues.
- Help them become educated that it's happening
- Educate yourselves. If possible in a formal program such as the Social Worker Program. Progress slowly yet surely. Advocate for programs and people that are effective.
- Be in the meetings with the health care team.
- Being able to get both primary care and mental health care together
- Better communication from county in local newspapers, cable TV, radio about what is going on. Don't keep using the same C/F members year after year after year. Rotate or expand.
- BE willing to speak up, refuse to be intimidated by mental health professionals, stand up for yourself, insist that your needs be met, and refuse to give in to those who feel the need to control.
- There need to be more informational dialogue sessions for consumers and family members to better understand coming changes and to strategize together about ways the new system can be designed to best serve the people.
- It takes skill, training, and education and a willingness to show up and if need be persistent to be heard, to get recognized and listened to. Not a lot of us have that capability.
- Talk to them face to care
- Through NAMI and stigma reducing events
- Show up. Volunteer to be on committees, policy, outcomes, QIC, even boards or commissions
- Like our MHSA stakeholder process but with greater transparency and clients and family members truly at the highest level in the planning process rather than just responding to proposals from administration
- Invite family members in churches, schools libraries, and community centers

4. **What would be the benefit of having clients and family members at the table during planning for integrating care and health care reform?**

- You can't get better information from clients and family members since they live the experiences everyday
- The benefit would be creating a welcoming environment that is user-friendly and that supports people to feel a sense of familiarity and inclusion. The benefit is to create a system that works while providing information and preventative services by peers who are non-judgmental and empathetic, easy to approach and share with. Time with
physicians can be better utilized when a knowledgeable peer has already coached a client/patient on what is important to report and which questions to ask.

- Next to the client themselves, the family members are a valuable resource for helping the client improve. Just like Hilary Clinton stated, It Takes a Village to Raise a Child. In the same vein, it takes a community of support to help a client get back to being who they were always meant to be.

_Cultural Competence_

- A huge difference in the way we look at it and how can we improve on the system of care, how we can improve on cultural competency, be educated on how it affect each other and the community around us.
- We would have the opportunity to influence those that think they know what is best for us. We also would have a sense of pride and accomplishment in a job well done. For the people, by the people, united we stand.
Family Member Responses

1. Are you or clients and family members involved in planning for healthcare reform in your county?

   The survey data shows that 52% of family members are not involved in planning for healthcare reform and 48% state they are involved in some way.

2. If yes, what kinds of involvement do clients and family members have?

   - Sit on county advisory councils. Attend local and regional conventions and conferences.
   - We go to rallies and meetings.
   - Myself (mother): Active in county NAMI as Family-to-Family, and Provider Education Teacher; Member County Mental Health Board; My son: Zero interest or involvement: ‘does not want to talk about it’

3. What are your recommendations for how clients and family members might be involved/more involved?

   - ASK THEM...
   - Provide input, be asked what they need
   - Stay friendly and approachable
   - Town hall meetings, focus groups
   - Someone to listen to family member concerns
   - NAMI would be our voice from the community...
   - Bring the meetings to the local level and serve a meal or hold the meetings where people pick up surplus food and five extra food or vouchers to those who attend
   - By being Asked, Respective, and Listened to. The family and patient voice has been minimal to non-existent over the past 13 years my son has been ill
   - I believe the family members should when they can be very proactive in the care of their family members
   - Set up open meetings that allow clients and family members to speak their mind directly and openly in the presence of providers, show how the provider system is responding to their comments

4. What would be the benefit of having clients and family members at the table during planning for integrating care and health care reform?

   - The clients and family members are most aware of what is needed for themselves.
   - Clients and family members are more aware of what services are needed and helpful for recovery
• As consumers always say, not about them, without them. I believe a lived history from both the point of view of the consumer and family members is the first building block to a better and more fully integrated system of care.
• Provide more holistic care; treat the whole person not just a piece
Provider Responses

1. Are clients and family members involved in planning for healthcare reform in your county?

Most providers, 56%, responded that clients and family members are not involved in planning for healthcare reform in their county.

2. If yes, what kinds of involvement do clients and family members have?

- None that I'm aware of...
- The planning is occurring in high levels of all of health services, and has not filtered down to mental health.
- I don't believe that the information has trickled down to that level. I think that when it does, we need to be prepared for the greater demand for services and therefore the demand for greater efficiencies. Clients and family members should be part of developing the solution in how limited resources will be divided up to meet the demand for services. We need to explain over and over and brainstorm solutions together.
- We are aware of some committees that involve input but have little knowledge of the extent of their involvement.
- Surveys, discussions...
- They have been involved in stakeholders meetings.
- Clients are getting more involved. Clients have formed a Client Coalition group

- Mental Health Advisory Board, NAMI, other meetings as scheduled
- Some are members of NAMI Urban Los Angeles, others are on advisory boards

Los Angeles County Provider

- Currently we have identified clients who may qualify but family members have yet to participate. We have just begun the process and are currently working on implementing a plan
- Clients have been identified for the 1115 Waiver but families are yet to be determined. The process recently began at the clinic, unable to give more information.

3. What are your recommendations for how clients and family members might be involved/more involved?

- Continue to get the word out to consumers and to encourage consumers to be involved in advocacy
- They could be directly interviewed by planners or asked to fill out questionnaires.
• Run ads to recruit new members. Consider paying members, even if minimal. Use part of budget for that payment - might bring in more C/F. Train C/F on how to effectively shape Board policy.
• Outreach programs, partnering with community leaders, going to the community centers rather than expecting them to come to government buildings, small groups rather than large ones.
• Join NAMI, got to public talks, read the newspapers, blogs etc., learn who their local policy makers are, call and write, join other nonprofit illness support groups, learn about government, and follow the money and into whose pockets it goes

• Stakeholder meetings, community meetings held at community centers, health fairs, to utilize media and the internet to do surveys

• As always, organized efforts are more effective than individual efforts. Combat stigma, isolation, and the prejudicial stereotypes that is common in both journalistic reporting and entertainment

*Information Technology*

• Local TV and radio ads, gatherings at church events and community events, including sports

*Responses from Children Providers*

• Public Education for early teens, young adults and family members
• Having family task force committees would be a good option

4. **What would the benefit be of having clients and family members at the table during planning for integrating care and healthcare reform?**

• Hearing the voices from the people that will be receiving direct services is beneficial so that health care reform can better fit the needs of the clients and those receiving services.
• Building Reality into the system--we can't do it without them
• Identifying the unmet needs of health care in the community to work on
• Having family members and clients at the planning table, helps understand both sides of integrating care and health care reform
• We'd have better plans.
Responses from Children Providers

- The same benefits we have seen from involving them in other processes; parent voice from the beginning ensures design success, parent ownership and true partnership that honor the parent perspective particularly when we disagree and then defer to their wisdom.

5. Are cultural groups that are un/underserved involved in planning for healthcare reform in your county? Is so, what kinds of involvement do they have? If not, how can these groups be involved more?

Of the total responses, 53% state that cultural groups are not involved in planning for health care reform.

- It is not clear how these groups are involved at the county level.
- Cultural groups need to be invited or access 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 ethic markets, newspaper, and advertisement in public transportation as to inviting them to be involved in their language to ensure everyone is aware of the healthcare reform in Santa Clara County.
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