

ASSESSMENT OF PEER-RUN/PEER-SUPPORTED SELF-MANAGEMENT PROGRAMS



Client and Family Sub-Committee

Improving Care – Transforming Lives - Together

**A Review and Preliminary Guidance
for Organizations Considering Implementation of
Self-Management Programs that
Support Integrated Care**

AUGUST 2011

This review was prepared by members of the Client and Family Sub-Committee of CalMEND, a program of the California Department of Health Care Services funded through the MHSA by the California State Department of Mental Health. The CalMEND Client and Family Sub-Committee and other CalMEND programs are provided and supported through a contract with the California Institute of Mental Health.

Team Members / Reviewers:

- Abigail Weissman, MSW
- Joyce Ott

Additional Reviewers:

- Karin Kalk
- Lea Nagy

Technical Assistance: Karin Kalk

CiMH CalMEND Project Director: Gale Bataille, MSW

INTRODUCTION

People with serious mental illness (SMI) die, on average, 25 years earlier than the general population.ⁱ Studies document recent increases in death rates over those previously reported. This is a serious public health problem for the people served by our state mental health systems. While suicide and injury account for about 30-40% of excess mortality, 60% of premature deaths in persons with schizophrenia are due to medical conditions such as cardiovascular, pulmonary and infectious diseases. People with schizophrenia and other serious mental illnesses (like bipolar disorder, major depression, and schizoaffective disorders) also suffer from a high prevalence of modifiable risk factors, in particular obesity and tobacco use. Compounding this problem, people with serious mental illness have poorer access to established monitoring and treatment guidelines for physical health conditions.

Health, mental health and substance use programs increasingly recognize that reversing these trends can only be achieved when services and supports are aimed at the whole person. These programs also recognize that their role in promoting clients' self-management of their conditions, whether physical, mental or otherwise, must be a prominent component of services and supports. Further, all efforts to promote self-management will be more effective if they are informed and supported by individuals with lived experience – and in many cases these services and supports are best led by peers.

We hope that the findings presented here will facilitate the research and selection of whole-health, peer-supported/led self-management programs in county programs, community agencies, consumer-run self-help groups, peer empowerment centers, or wellness centers seeking to reduce the modifiable risk factors and physical conditions with which their clients contend.

APPROACH

In order to provide this guidance, we identified and evaluated self-management programs that met the following criteria:

- Whole-health in scope: range of components addresses array of health need
- Evidence-based (or promising)
- Peer-run and/or peer-supported
- Readiness for/ease of implementation
- Supports individualized needs

Due to limited resources, we performed only a preliminary investigation of promising programs. Therefore, the following caveats are critical when considering our findings:

- This review was not exhaustive; in all likelihood there are more, maybe many more, promising programs than were considered here.
- Reviewers did not participate in any of these programs, rather their findings are based on readily available published materials describing the programs.

The promising programs selected based on the above criteria included:

1. **Peer Support Whole Health (PSWH):** PSW “is a peer-driven plan for transformation of the mental health system. In this approach, a peer specialist helps a peer choose and record a health goal in an individual service plan funded by Medicaid-billable peer support and provides peer support to help reach that goal.”ⁱⁱ
2. **NAMI Hearts And Minds:** “The NAMI Hearts & Minds program is an online, interactive, educational initiative promoting the idea of wellness in both mind and body. Wellness is an ongoing process of learning how to make choices that support a more successful, healthy life.”ⁱⁱⁱ
3. **Solutions for Wellness (SFW):** SFW is a 6-month course in which “patients receive support, counseling, and tools to help them improve diet, exercise, stress management, and sleep habits—all tailored to their unique needs.” The SFW program features: Personalized Meal & Exercise Plans, Dietitian Counseling Service, Dietitian Helpline, Newsletters and Motivational Progress Updates.^{iv}

Two additional programs were also evaluated, although to a lesser extent:

- **Wellness Self-Management (WSM):** “Wellness Self-Management is a curriculum-based clinical practice designed to assist adults to effectively manage serious mental health problems. The topics covered include a number of research-informed approaches that are organized into a comprehensive and coordinated set of practices. The WSM program is based on Illness Management and Recovery (IMR)” and “includes lessons emphasizing the connection between physical and mental health.”^v
- **Facing Us Club House:** “FacingUs.org is an online community created to provide a safe haven for those living with mood disorders and offer inspiration and encouragement to anyone seeking personal wellness.” Once inside the Clubhouse, users can, among other things, “create a wellness book filled with tips for maintaining a healthy life. These tips can be a combination of personal tips and those chosen from a library of shared tips posted to the site by other users.”^{vi}

Reviewers (four) used a modified Delphi Process to identify the strengths and weakness of each of the selected programs. The process enabled the work group to consider each of the programs from a variety of perspectives and variables, and rate each on a 1 (strongly disagree) to 9 (strongly agree) scale. See Appendix A for a more detailed description of the review process. Reviewers included client, family, and administrative representatives.

RESULTS

The table below summarizes the median scores for each program in each of the evaluation categories. Specific comments about each category are provided in Appendix B.

| PROGRAMS: | Meaningfulness for Clients | | | | Organizational Feasibility | | | | Overall |
|---------------------------|----------------------------|-----|-------------------|---------|----------------------------|--------|----------|--------------|---------|
| | Import-ant | Gap | Culture/Diversity | Outcome | Specified | Burden | Literacy | Develop-ment | |
| Peer Support Whole Health | 8.5 | 7.5 | 4.0 | 8.0 | 9.0 | 6.5 | 6.5 | 6.0 | 8.0 |
| Hearts And Minds | 8.0 | 3.5 | 3.5 | 4.5 | 3.5 | 5.0 | 5.5 | 1.0 | 5.5 |
| Solutions for Wellness | 7.5 | 7.0 | 5.0 | 6.5 | 2.5 | 7.5 | 6.0 | 3.0 | 7.5 |

The following briefly summarizes key strengths and potential drawbacks for each program.

1. Peer Support Whole Health (PSWH)

Strengths:

- Strongest of the three programs evaluated
- Led by peers with mental health lived experience provides an extensive manual for facilitators as well as workbook for participants.
- Evidence-based^{vii}; in published research, significant improvements found in client “activation”/self-mangement and ability to access to primary care.
- Consistent with recovery values of choice, self-direction and peer support
- Helps people set, achieve and maintiain goals that lead to healthier lifestyles and promote wellness

Potential Drawbacks:

- Attention to mental health concerns is minimal, especially compared to physical health
- May have limitations with diverse populations (materials not multi-lingual)

2. Hearts And Minds

Strengths:

- Hearts and Minds pamphlet, as well as a facilitator’s guide, are available online
- Content has the potential to advance health literacy (likely most beneficial to health care professionals)

Potential Drawbacks:

- Written almost exclusively by doctors; no evidence of client or family input.
- The Hearts and Minds pamphlet is very technical, difficult to grasp, overly academic
- May have limitations with diverse populations (materials not multi-lingual)

3. **Solutions for Wellness**

Strengths:

- SAMHSA's 10X10 Wellness Campaign site includes a link to SFW
- Free, personalized six-month online support program
- Client has option of sharing SFW data with referring health care professional
- Dietician is available by phone to participants

Potential Drawbacks:

- Not entirely independent/stand-alone; provider must enroll and provide referral
- Appears to have high drop-out rate
- Some may be reluctant/not able to use due to pharmaceutical company affiliation (although it does not promote any particular medication or medication use)
- May have limitations with diverse populations (materials not multi-lingual)

As mentioned above, two additional programs were considered, but not selected for full review because they did not sufficiently focus on physical health as well as mental/emotional health. Key strengths and potential drawbacks for these are described below.

4. **Wellness Self-Management (WSM)**

Strengths:

- Peers can easily facilitate lessons; peer input helped shape modifications of this workbook
- Personal workbook is available in Spanish and English; overall strong emphasis on cultural awareness, including role of community, and religious and family values
- Addresses the connection between healthy life style and mental health recovery

Potential Drawbacks:

- Dedicates more time and space to mental health than to physical health or general well-being.
- Workbook is long (however, individual lessons and/or sections could be of value)

5. **Facing Us Clubhouse**

Strengths:

- Online, user-friendly, interactive, available to anyone who wishes to use it
- Developed by peers
- Enables peers to share ideas and tips with each other about their lives, including a Media Room and a Creativity Center.
- Information and tips are offered on many topics such as Managing Triggers, Crisis Management, Daily Self Care, and Physical Health

Potential Drawbacks:

- Heavily weighted toward mental, spiritual and emotional well-being; has minimal physical health promotion and self-management

CONCLUSION

In general, the reviewers felt that none of the programs would effectively support all clients, especially given the wide range of clients' needs in terms of stage of recovery; physical conditions; culture, race and ethnicity; socio-economic conditions; spiritual and religious preferences, and other demographic differences. Self-management support of clients' whole health will likely require a variety of peer led or supported programs.

ⁱ Morbidity and Mortality in People with Serious Mental Illness 2

ⁱⁱ Fricks, L. (2009). Consumers Take Charge of Wellness. National Council Magazine 20-21.

ⁱⁱⁱ http://www.nami.org/template.cfm?section=Hearts_and_Minds

^{iv} www.solutionsforwellness.info

^v <http://www.nyebpcenter.org/WellnessSelfManagementWSM/tabid/118/Default.aspx>

^{vi} www.facingus.org

^{vii} Benjamin G. Druss, MD, MPH, Liping Zhao, MSPH, Silke A. von Esenwein, PhD, Joseph R. Bona, MD, MBA, Larry Fricks, Sherry Jenkins-Tucker, Evelina Sterling, MPH, CHES, Ralph DiClemente, PhD, and Kate Lorig, RN, DrPH, "The Health and Recovery Peer (HARP) Program: A Peer-Led Intervention to Improve Medical Self-Management for Persons with Serious Mental Illness," [Schizophr Res. 2010 May; 118\(1-3\): 264-270.](http://www.schizophrenia.com)

APPENDIX A: Assessment Process

Four reviewers evaluated the programs using the categories below.

| PROGRAMS: | Meaningfulness for Clients | | | | Organizational Feasibility | | | Development | Overall |
|---------------------------|----------------------------|-----|-----------------------|---------|----------------------------|--------|----------|-------------|---------|
| | Important | Gap | Culture/ Diversity | Outcome | Specified | Burden | Literacy | | |
| Peer Support Whole Health | | | | | | | | | |
| NAMI Hearts And Minds | | | | | | | | | |
| Solutions for Wellness | | | | | | | | | |

The process enabled the work group to consider each of the program from a variety of perspectives and variables using a 1 (strongly disagree) to 9 scale (strongly agree).

Terms were defined as follows:

Meaningfulness for Clients

- **Important:** This program addresses an area of self-management for clients' whole health important to my stakeholder group*
- **Gap:** This program addresses an area where there is often a gap between actual and ideal self management of whole health
- **Culture/Diversity:** This program supports a diverse array of clients (age, ethnicity, sex, literacy, language)
- **Outcome:** Improved self-management using this program is likely to be associated with better whole health (mental health, physical health and substance use) NOTE: Evidence basis should be considered here

Organizational Feasibility

- **Specified:** The program components delineate role(s) for peers to support, facilitate or otherwise promote its use for client self-management
- **Burden:** Adoption of this program represents a low burden to health organizations (ease of implementation, cost of operating, etc.)
- **Literacy:** The program supports a wide array of health literacy (the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions)

Overall

- **Development:** Peer involvement in the programs' development
- **Overall:** Overall, this program should be included in mental health/ primary care/ substance use integration projects' efforts to support self-management

APPENDIX B: Table of Results

| | Meaningfulness for Clients | | | | Organizational Feasibility | | | | |
|---|--|--|---|---|--|---|--|---|---|
| | Important | Gap | Culture/ Diversity | Outcome | Specified | Burden | Literacy | Development | Overall |
| PROGRAMS: | This program addresses an area of self-mgmt for clients' whole health important to my stakeholder group* | This program addresses an area where there is often a gap** between actual and ideal self-management of whole health | This program supports a diverse array of clients (age, ethnicity, sex, literacy, language) | Improved self-mgmt using this program is likely to be associated with better whole health (mental health, physical health and substance use) | The program components delineate role(s) for peers to support, facilitate or otherwise promote its use for self mgmt | Adoption of this program represents a low burden to health organizations (ease of implementation, operating cost, etc.) | The program supports a wide array of health literacy *** | Peer involvement in the programs' development | Overall, this program should be included in mental health/ primary care/ substance use integration projects' efforts to support self mgmt |
| Peer Support Whole Health (Turn-key program with multiple modalities) | Median Score = 8.5 Comments: Strongly oriented to physical health; mental health collaboration is not as well addressed | Median Score = 7.5 Comments: Goes a long way to address the gap, but falls short in terms of mental wellness and challenges with ADLs (access to recommended food, shelter/ home, etc.) | Median Score = 4.0 Comments: Very limited in its use and adaptability with different groups, whether it be by age, socio-economic status, ethnicity, literacy, etc. | Median Score = 8.0 Comments: The "Five Keys to Success" are very inclusive and supportive of accountability and therefore likely to generate good outcomes for those who elect to join the program. | Median Score = 9.0 Comments: Peer supporters/ facilitators are mental health clients, which may enhance connection of mind, body, spirit issues. Peer role is well developed, clear & supported with tools, instruction, etc. | Median Score = 8.0 Comments: Clear training and support materials are ready/turn-key; adopting organizations will need a strong, meaningful integrated peer culture to reliably achieve success. | Median Score = 8.0 Comments: Content related to literacy is lacking, however, this may be mitigated by the group approach which is likely to foster discussion and learning around healthy living | Median Score = 7.0 Comments: At least one, well respected, peer was central to its development; additional peer involvement is unclear. | Median Score = 8.0 Comments: Best of the 3 programs reviewed and highly recommended. |
| NAMI Hearts And Minds (On-line resources) | Median Score = 8.0 Comments: Strongly oriented to physical health, but missing relaxation and stress; mental health collaboration is not as well addressed | Median Score = 3.5 Comments: Very academic approach to whole health and only suited to a small portion of well clients. Lacks motivating spirit and engagement. | Score = 3.5 Comments: Extremely limited in its use and adaptability with different groups, whether it be by age, socio-economic status, ethnicity, literacy, etc. | Median Score = 4.5 Comments: As a stand-alone program, this is not likely to improve self-management and whole health. Program materials may be useful adjuncts and references. | Median Score = 3.5 Comments: Material not well suited for peer support and/or peer led/facilitated programs. | Median Score = 5.0 Comments: Has some tools to operationalize; highly scripted. Very limited tools and supports for day to day use. Tools and content may be most useful for providers. Burden is low if clients simply referred to read pamphlet. | Median Score = 5.5 Comments: Content is written at very high literacy level with an academic tone. Content is geared to advancing health literacy, but its structure and language is not understandable to a wide ranging audience. | Median Score = 1.0 Comments: No evidence that peers were involved in any part of this program's development. | Median Score = 5.5 Comments: This program has very limited utility and lacks appropriateness for the spirit and approach best suited for promoting whole health. |
| Solutions for Wellness (Interactive on-line program) | Median Score = 7.5 Comments: Strongly oriented to weight management but may fall short in other topics necessary for whole health, particularly in some aspects mental health. Offers option of nutritionist and communication of progress to the referring MD. | Median Score = 7.0 Comments: Requires existing connection with a physician to gain access to the program, so won't work for clients who don't have access to a physician. The client may invite their MD to be involved, and MD may choose to review results with the client. | Median Score = 5.0 Comments: May be limited in its use and adaptability with different groups (e.g. age, socio-economic status, ethnicity, literacy, geography, etc.). May have a 'one-size-fits-all' orientation. | Median Score = 6.5 Comments: High drop-out rates are reported. For very motivated and independent clients; this is likely to be an effective stand-alone program. For others, the addition of peer support will be key in achieving success. Not likely to be useful for individuals with housing problems or limited resources for food, etc. | Median Score = 2.5 Comments: Not peer-supported by design, as it is an interactive on-line program. However, it could be used in various peer activities to supplement peer-supported whole health efforts. | Median Score = 7.5 Comments: Burden is low if physician simply assigns client a number so that client can enroll in online program. If to be used in peer-support activities, additional on the ground program development will be required. | Median Score = 6.0 Comments: On-line communications are in multiple modalities (reading, video, audio, etc.), although available only in English. | Median Score = 3.0 Comments: No known peer involvement in development; development was funded by Eli Lilly, which may or may not have been involved in creation of actual content. | Median Score = 7.5 Comments: This program is very valuable for some clients, although has greater potential if operationalized with peer support. |

APPENDIX C: Resources/Weblinks

PEER SUPPORT WHOLE HEALTH (PSWH)

- Source: Originally developed by the Appalachian Consulting Group
- Resource Links:
 - <http://www.nasuad.org/documentation/hcbs2010/PowerPoints/Tuesday/Peer%20Support%20Whole%20Health,%20Recovery%20and%20Transition.pdf>
 - www.nasmhpd.org/general_files/Technical%20Assistance/TTIY1Y2Summary.pdf (pages 9-10)

HEARTS AND MINDS

- Source: from the National Alliance for Mental Illness (NAMI)
- Resource Links:
 - http://www.nami.org/template.cfm?section=Hearts_and_Minds
 - http://www.nami.org/Template.cfm?Section=Hearts_and_Minds&Template=/ContentManagement/ContentDisplay.cfm&ContentID=94415

SOLUTIONS FOR WELLNESS (SFW)

- Source: developed by ELI LILLY Pharmaceutical Company
- Resource Links: www.solutionsforwellness.info

WELLNESS SELF-MANAGEMENT (WSM)

- Source: Personal Workbook developed by the New York State Office of Mental Health (NYSOMH); The Urban Institute for Behavioral Health (UIBH); Center for Practice Innovations (CPI) New York State Psychiatric Institute
- Resource Link: <http://www.nyebpcenter.org/WellnessSelfManagementWSM/tabid/118/Default.aspx>

FACING US CLUB HOUSE

- Source: from the Depressions and Bipolar Support Association (DBSA)
- Resource Links:
 - www.facingus.org
 - www.dbsalliance.org/site/PageServer?pagename=home