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

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.

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INTRODUCTION
People with serious mental illness (SMI) die, on average, 25 years earlier than the general population. 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.”

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.”

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.
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.”

- **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.”

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.

<table>
<thead>
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<th>PROGRAMS:</th>
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<th>Organizational Feasibility</th>
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<td>Import -ant</td>
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<td>8.5</td>
<td>7.5</td>
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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 extensice manual for facilitators as well as workbook for participants.
     - Evidence-based; in published research, significant improvements found in client “activation”/self-management and ability to access to primary care.
     - Consistent with recovery values of choice, self-direction and peer support
     - Helps people set, achieve and maintain 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 commity, and religious and family values
- Addresses the connection between healthy lifestyle 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 religios preferences, and other demographic differences. Self-management support of clients’ whole health will likely require a variety of peer led or supported programs.

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1. Morbidity and Mortality in People with Serious Mental Illness
4. [www.solutionsforwellness.info](http://www.solutionsforwellness.info)
6. [www.facingus.org](http://www.facingus.org)
APPENDIX A: Assessment Process

Four reviewers evaluated the programs using the categories below.

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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

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<td>Peer Support Whole Health (Turn-key program with multiple modalities)</td>
<td>Median Score = 8.5 Comments: Strongly oriented to physical health; mental health collaboration is not as well addressed</td>
<td>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.)</td>
</tr>
<tr>
<td>NAMI Hearts And Minds (On-line resources)</td>
<td>Median Score = 8.0 Comments: Very academic approach to whole health and only suited to a small portion of well clients. Lacks motivating spirit and engagement.</td>
<td>Median 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.</td>
</tr>
<tr>
<td>Solutions for Wellness (Interactive on-line program)</td>
<td>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.</td>
<td>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.</td>
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APPENDIX C: Resources/Weblinks

PEER SUPPORT WHOLE HEALTH (PSWH)
- Source: Originally developed by the Appalachian Consulting Group
- Resource Links:

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

FACING US CLUB HOUSE
- Source: from theDepressions and Bipolar Support Association (DBSA)
- Resource Links:
  - [www.facingus.org](http://www.facingus.org)
  - [www.dbsalliance.org/site/PageServer?pagename=home](http://www.dbsalliance.org/site/PageServer?pagename=home)