Defeating Isolation and Social Exclusion Through Peer Empowerment: Part 3

It’s My Life ~ Social Explorations
Facilitating Recovery through Social Self-Directed Care

Mental Health America
#B4Stage4
It’s My Life ~ Social Self-Directed Care is a program of Mental Health America

MHA is the nation’s oldest advocacy organization addressing the full spectrum of mental health and substance use conditions and the profound impact they have on public health and our society. MHA was established in 1909 by a mental health peer, Clifford W. Beers.

We focus on: prevention for all; early identification and intervention for those at risk; integrated health and behavioral health care for those who need it; and recovery as a goal. The National Headquarters for MHA successfully launched the It’s My Life ~ Social Explorations Program in the Northern Virginia area.
Presented By:
Shavonne G. Carpenter, CPRS

Shavonne has had extensive training as a Certified Peer Support Specialist and in Counseling. She also has experience dealing with co-occurring disorders and working with individuals with intellectual disabilities. She takes a personal and individualized approach to peer support. Shavonne takes pride in having the Spirit to hold the space for others to discover and show their greatness.

As a Peer Life Coach, she led program participants through social skill development, community involvement and self-direction. She also contributed to the writing of the Program Manual and Participant Handbook. Shavonne currently serves as the It’s My Life: Social Self-Directed Care Head Life Coach Trainer, conducting the trainings now being offered by Mental Health America to equip organizations to operate the IML Program and teach their Peer Specialists to become IML Peer Life Coaches.
IML’s Purpose

- Advance recovery and improve the lives of individuals with severe psychiatric conditions with a focus on some of the most isolated, misunderstood members of our communities.
- Assist peers in finding their power to reclaim their place in the community.
- Provide a safe place for individuals to learn and practice skills to prepare themselves as they move forward on their chosen recovery path.
- Participants are accompanied on their recovery journeys by trained Peer Life Coaches who help them bridge the gap to a larger social world.
Social Connection Fits Into The Overall Goal and Journey of Recovery

The It’s My Life Program is designed to help build networks of friends and intimate relationships, thus creating a strong social support system. It also helps to increase self-esteem and self-worth to improve overall social functioning.

Ultimately, the Program uses the self-directed care model to help the participants set and reach social and personal goals that may include going back to school, finding a volunteer position, or even employment.
Social Connection Fits Into The Overall Goal and Journey of Recovery

- The piloting of this program focused on individuals with schizophrenia or schizoaffective disorder, because they are among the community’s most isolated and marginalized.

- Schizophrenia affects how a person thinks, feels and acts. Someone with schizophrenia may experience difficulty distinguishing what is real from what is imaginary; may be unresponsive or withdrawn; and may have a hard time expressing “normal” emotions in social situations. Individuals with schizoaffective disorder may encounter similar troubles in addition to a mood disorder.
Social Connection Fits Into The Overall Goal and Journey of Recovery

- Given the complexity of these conditions and that social functioning impairments occur at all stages of the illness, the need for innovative approaches in helping to develop social skills, friends, and intimate relationships is particularly acute for people with schizophrenia.

- Although the piloting of this program focused on individuals with schizophrenia or schizoaffective disorder, the principles and practices of Social Self-Directed Care can be applied with any mental health diagnosis.
Evaluation Techniques: Personal Outcome Measures

- **PERSONAL**: Starts with the person’s own view of their life
- **OUTCOME**: Defines what is important to the person
- **MEASURES**: Offers objective determination of whether people are getting what is personally important

Instead of looking at the quality of how the services are being delivered, Personal Outcome Measures® look at whether the services and supports are having the desired results or outcomes that matter to the person.
**Personal Outcome Measures Results**

Increase in quality of life as described by participants

<table>
<thead>
<tr>
<th>POM Statement</th>
<th>Initial Score (%)</th>
<th>Final Score (%)</th>
<th>Change % Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-People are connected to natural support networks</td>
<td>25%</td>
<td>75%</td>
<td>50%</td>
</tr>
<tr>
<td>2-People have intimate relationships.</td>
<td>25%</td>
<td>63%</td>
<td>38%</td>
</tr>
<tr>
<td>5-People exercise rights</td>
<td>63%</td>
<td>88%</td>
<td>25%</td>
</tr>
<tr>
<td>6-People are treated fairly</td>
<td>50%</td>
<td>75%</td>
<td>25%</td>
</tr>
<tr>
<td>11-People use their environments</td>
<td>13%</td>
<td>88%</td>
<td>75%</td>
</tr>
<tr>
<td>14-People interact with other members of the community</td>
<td>25%</td>
<td>63%</td>
<td>38%</td>
</tr>
<tr>
<td>15-People perform different social roles</td>
<td>25%</td>
<td>63%</td>
<td>38%</td>
</tr>
<tr>
<td>17-People choose personal goals*</td>
<td>100%</td>
<td>80%</td>
<td>-20%</td>
</tr>
<tr>
<td>18-People realize personal goals</td>
<td>63%</td>
<td>67%</td>
<td>5%</td>
</tr>
<tr>
<td>19-People participate in the life of the community</td>
<td>0%</td>
<td>75%</td>
<td>75%</td>
</tr>
<tr>
<td>20-People have friends</td>
<td>0%</td>
<td>63%</td>
<td>63%</td>
</tr>
<tr>
<td>21-People are respected</td>
<td>75%</td>
<td>88%</td>
<td>13%</td>
</tr>
</tbody>
</table>

*According to participants, setting their own goals in this program made them realize how many of their other goals were set for them.*
Personal Outcome Measures Results

Increase in quality of life as described by participants

*According to participants, setting their own goals in this program made them realize how many of their other goals were set for them
Evaluation Techniques: Satisfaction Surveys

- Provides participants an avenue to anonymously provide feedback about the program and coaches
- Mailed to all participants with BRE included
- Completed at mid-point and end of program
Satisfaction Surveys Results

Of the 17 participants who completed the survey, 95% rated their satisfaction with the program with the highest possible rating.

<table>
<thead>
<tr>
<th>For the following statements, please check the box that best reflects how you feel.</th>
<th>Definitely Agree</th>
<th>Somewhat Agree</th>
<th>Somewhat Disagree</th>
<th>Definitely Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>My Coach is willing and able to meet me where I choose</td>
<td>15</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>My Coach has explained to me how they can and cannot assist me</td>
<td>15</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>When I need help I know who I can call to get support</td>
<td>17</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>I feel respected and listened to by my coach</td>
<td>15</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>The money for the program is assisting me to reach my social goals</td>
<td>15</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>My coach works in partnership with me to reach my social goals</td>
<td>17</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>I am satisfied with the help I have received from my coach</td>
<td>17</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>The services I have received have helped me reach my social goals</td>
<td>15</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>My coach is sensitive to my cultural and ethnic background</td>
<td>17</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>I think my coach supports my well being</td>
<td>17</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Overall I feel that my social life is getting better because of the program</td>
<td>16</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
Guided Journals

We also use “guided journaling” as a measure of increased quality of life. Participants maintain a weekly journal talking about their activities and their reactions to them. The journal includes a number of set questions that helps the individual to look at their activities and their relationships to their goals.

From the journal, it can be determined if the program has an effect on someone’s overall wellbeing.
Guided Journals Results

As people progress towards achievement of their goals they often see that the goal they have identified is a stepping stone to a higher goal with the potential for an increased impact on their day to day life, their feelings of pride for what they have achieved, and optimism about the future.

“I think the combination of going to drawing class, seeing my coach, and journaling is like practicing and I have been seeing improvements. I feel more confident, clear minded, and out-going”.
Guided Journals Results

From the journal entries it was observed that when Participants realize that they are more than capable of learning new skills and responding appropriately to social stimuli, they have a boost in self-confidence.

“At my DBSA group, I had a conversation with a co-attendee. She asked me if I would like to go to get coffee or dinner. I tried to be more positive by responding yes, and we exchanged phone numbers.”
Evaluation Techniques:
Hospitalization Rates

- Past hospitalizations from the 2 years prior to enrollment in the program were documented with informed consent provided by each participant.
- Any re-hospitalizations that occurred during participation in the program were also documented accordingly.
- Note was also taken of any changes in services that participants received while in the program.
Hospitalization Rates Results

- In the two years prior to entering the Social Self-Directed Care Program, participants had experienced a total of 15 hospitalizations. In the 19 months of activities, 1 member had experienced a single hospitalization.

- Aside from joining the It’s My Life Program, participants had no other changes in the services they were receiving.
Tools and Innovation in IML

- Peer Support
- Self-Directed Care
- Psychiatric Rehabilitation
- Life Coaching
IML’s Process: Overview

- Life Coach Training
- Recruitment
- Forming Partnership
- Skill Building
- Outings
- Evaluation Techniques
- Results
Participants were given the opportunity to select their own Life Coach, given they were of the same gender.

Participants were introduced to all available Coaches to determine their level of “peer-ness” and compatibility; who they could relate to most. This included the sharing of the Coaches’ biographies.

The male/female dynamic was taken into consideration to avoid transference and counter-transference.
The strength of the peer relationship is enhanced through regular meetings and strategic self-disclosure.

Solidarity and credibility are built through empathy, honesty and authenticity.

The coach is both a mentor and a friend.
When people are excluded from the day to day activities of their community, whether by the effects of illness or by societal discrimination, they either lose or never learn the skills necessary to successfully navigate socially or to seek out, initiate, and form new bonds and friendships.

Coaches assist individuals in identifying interesting activities in the community, learning where they are available, and then participating in those activities which give them opportunities to meet other people with similar interests.
Goal Setting in IML

- Peer Life Coaches also assist participants with setting social goals
- Together they:
  - Evaluate Participant’s feelings about current social standing
  - Assess hobbies, interests and community involvement and the accessibility of them
  - Explore creative solutions to barriers
Goal Setting in IML

During weekly/bi-weekly meeting, the participant and their Peer Life Coach will:

- Engage in friendly conversation, effective listening and sharing experiences
- Determine and discuss the three social goals of the Participant
  - All social activities must go back to the three social goals made
  - These social goals can change over time, even on a monthly basis, especially once these goals are met
Goal Setting in IML

- Once the Participant has established their social goals and come up with a plan to accomplish them, the Coach assists them with carrying out their plans.

- The Coach provides encouragement, support and feedback to the Participant as they work together in partnership.
Goal Setting in IML

- Participants receive a monthly allowance of $60.00 to be spent on advancing toward the three (3) social goals that were set with the assistance of the Life Coach.

- The amount is pending completion of weekly guided journaling and consistently providing proof of purchase (receipts) for how the money was spent.

- All expenditures must correlate to the social goals, action plan and spending plan. Activities must be approved by the Life Coach and the Program Director.
Goal Setting in IML: Examples

- “Learning socially acceptable talk in public places”
- “Enjoy self in social situations (like Thanksgiving dinner)”. 
- “Get out of the house more often”
Goal Setting in IML: Examples

- “Making and meeting new friends”
- “Work on a new hobby (Baking)”
- “Join and complete a drawing class”
- “More talkative/social”
- “Give back to the community”
Sessions With The Coach

- As individuals begin to identify their social goals and activities that interest them, the coach frequently accompanies them into the community.
- They may meet regularly for a cup of coffee and conversation, or they might attend an event in the community.
Sessions With The Coach

- When not on outings, visits are spent reviewing journaling, goals, skills sets and handouts/worksheets that will assist the participant in progressing toward their identified social goals.

- Life Coaches will be a safe sounding board for participants to express themselves and work through challenges.
Sessions With The Coach:  
Skill Building

IML Peer Life Coaches provide guidance and education for new social-life skills in several different areas, including:

- Identifying areas of participant’s interests
- Collaborating in decision making with the participants
- Budgeting a spending account and attending social activities
Sessions With The Coach: Skill Building

IML Peer Life Coaches provide guidance and education for new social-life skills in several different areas, including:

- Assisting in building community inclusion
- Help form and enhance healthy friendships and intimate relationships
- Coaching and feedback regarding progress
- Building connections to employment or volunteerism, if desired
Sessions With The Coach:  
Skill Building

IML Peer Life Coaches provide guidance and education for new social-life skills in several different areas, including:

- Communication
- Emotion Regulation
- Effective Listening
- Self-Care
Sessions With The Coach:  
Skill Building

IML Peer Life Coaches provide guidance and education for new social-life skills in several different areas, including:

- Personal Boundaries
- Understanding social norms
- Various other skills as they are discovered and the Participant feels they are necessary for positive social interaction
IML Participant - Peer Coach Relationship

- Coaches model how friends interact through conversation and activities
- When coaches model the qualities that form friendships the participants learn not only how to be a friend but also to recognize when someone is a true friend
They learn that friends are honest, understanding, supportive, and loyal. They learn that having friends is both a gift and an obligation.

When many people talk about their recovery they often say that the most important single thing is to have at least one person who believes in them, one friend.
By continuing to participate in activities shared with people with similar interests people build familiarity with one another and seemingly insurmountable social barriers are overcome.

Repeated exposure to experiences and other people lessens the feelings of social anxiety and shyness so often felt by those of us who have experienced isolation and social exclusion.

For some of us, initiating a conversation with a stranger can open doorways to developing connections in the community.
IML Participant - Peer Coach Relationship

- Recruitment & Coach Training
- Forming of Partnership
- Skill Building
- Outings
- Outcomes
- Results

KEY
- Participant
- Life Coach
- Social Network
While enrolled in IML, this participant set a goal to increase what she referred to as her “intellectual property”. As part of that, she wanted to learn how to use a camera. She saved part of her stipend for months and was able to purchase her own digital camera. She now records the services at her local church in the media ministry.
While enrolled in IML, this participant set a goal to increase her social/support network. She is now a Certified Peer Recovery Specialist and Advanced WRAP Facilitator. Using the skills she learned and her own lived experiences, she has also facilitated other Mental Health Recovery Groups and is employed part-time.
While enrolled in IML, this participant set a goal to improve and share her musical talents. She used her stipend to purchase sheet music and now volunteers at a local Senior Living Facility playing the piano for the residents.
Conclusions

- The It’s My Life Social Self-Directed Care Program is highly relevant to any whole health approach to behavioral health.

- Savings in the reduction of emergency services, increased overall health, and lowered re-hospitalization rates makes this an affordable service for managed care and state funded programs.

- The program would also be ideal for operation by a peer-run organization.
Conclusions

Having focused on one of the most marginalized populations and receiving such remarkable results, it would be a reasonable expectation that even greater outcomes would be achieved for individuals with less complicated mental health challenges.
Conclusions

- The It’s My Life ~ Social Self-Directed Care Program is an integrated skill and support strategy designed to help individuals with SMI to build networks of friends and intimate relationships, thus creating a strong social support system.

- This in turn helps the Participant to become an active member of the community and feel less isolated which also helps to increase self-esteem and self-worth, improving overall social functioning and health.

- The increase of overall health has shown to decrease the need for hospitalization as well as avoiding premature death.
Conclusions

- It’s My Life is a unique program that has been highly successful in assisting people to end isolation and feelings of social exclusion.

- Our participants have found new meanings in their lives and have gone on to build lasting relationships and connections to their communities.

- The most important aspects of the program have been the nature of the peer relationship, establishing meaningful goals and action steps to achieve them, and breaking down the barriers that have prevented people from finding friendships and connectivity in the community.
Mental Health America’s Vision for the Future of Social Self-directed Care as Part of Recovery

- Our goal for the future is to see It’s My Life implemented across the country. The program effectively addresses the need each of us has to build friendships and connections to our communities, and self-direction empowers us to take control of our destinies.

- Social inclusion is about being able to participate in and contribute to social life - in economic, social, psychological, and political terms. To do this requires having personal capacity as well as access to a range of social roles. Merton, R., Bateman, J. (2007)
Implementing IML

The It’s My Life Program is suitable to be operated by:

- Peer-Run Organizations
- State Mental Health Establishments
- Community Service Boards or Mental Health Centers
- Church Organizations
- MHA Affiliates
- NAMI Groups, etc.
Implementing IML: Getting Started

The following are needed in order to get started:

- Fidelity to all of the basic principles of the IML model, especially remaining truly self-directed
- Attending MHA’s three-part Training Webinar
- Community Resources
Implementing IML: Getting Started

The following are needed in order to get started:

- The IML Training Manual, Participant Handbook and Handouts
- Peer Support Specialist(s)
- Program Director
- Funding - possible sources could include:
  - State Mental Health Authorities
  - Community Service Boards
  - Community Mental Health Centers
  - Philanthropic Organizations
Implementing IML: Funding

The pilot program was funded by Mental Health America and a grant from Janssen Pharmaceutical Companies.

Funds were used for:
- Salaries for program staff
- Training of Coaches
- Program materials (binders, printing, etc.)
- Social Budget for participants
- Reimbursing Coaches for cost of travel and outings with participants
Implementing IML: Training

Mental Health America’s experienced Peer Life Coaches are available for individual or group training in-person, by phone or video calls.
Implementing IML: Training

- Virtual trainings are FREE!
- In-person training is also available for a reasonable fee.
Implementing IML: Training

Training provided by MHA identifies key parts of:

- Peer Support
- Shared Decision-Making
- Center for Psychiatric Rehabilitation from Boston University Online (http://www.bu.edu/cpr/training/distance/courses)
- Life Coaching: Becoming a Professional Life Coach: Lessons from the Institute of Life Coach Training by Patrick William and Diane Menendez
- Motivational Interviewing: (http://www.motivationalinterviewing.org)
Implementing IML: Training

Training provided by MHA includes:

- Flexible scheduling to meet the needs of your team
- Training Kit
- Individual instruction sessions for the Program Director
- Technical assistance after implementation
Implementing IML: Training

Training provided by MHA includes helping your coaches:

- Learn the tools and how to use them
- Learn how to work with people who have social challenges
- Understand Boundaries
- Incorporate self-care in their services
Implementing IML: Training

- MHA is also introducing “It’s My Life: Social Explorations - The Support Group Format)

- This new format will allow organizations to reduce their expenses in implementing IML

- Training will include additional resources relating to support groups
Would like to thank

Mental Health America

for providing the grants to train other organizations to end social exclusion and isolation through the It's My Life: Social Self-Directed Care program.
Defeating Isolation and Social Exclusion Through Peer Empowerment

MHA’s It’s My Life: Social Explorations Program

For Additional Information
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