Defeating Isolation and Social Exclusion Through Peer Empowerment: Part 2

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

center for peer support
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
Definition of Community Inclusion

- The opportunity to live in the community and be valued for one’s uniqueness and abilities, like everyone else (Salzer, 2006)

- To promote inclusion, we need pathways from segregated service provision into mainstream services: groups or activities solely for persons with mental health problems may reinforce segregation unless they are part of a supported pathway into mainstream services accessed by everyone (www.socialinclusion.org.uk)
Principles of Community Inclusion

1. Rights - Shifting from ‘least restrictive’ to ‘most inclusive’ is a growing federal mandate

2. Roles - Rights and responsibilities must be viewed across a wide range of ‘life domains’
Principles of Community Inclusion

3. Responsibilities - Community inclusion implies the consumers’ assumption of varied responsibilities

4. Choice - responding to each individual’s set of community inclusion priorities and concerns about the pace of change
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.
IML’s Process: Overview

- Life Coach Training
- Recruitment
- Forming Partnership
- Skill Building
- Outings
- Evaluation Techniques
- Results
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

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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>
Evaluation Techniques: Guided Journals

In addition to a summary of their week, the journal has probing questions that are intended to get at how these social interactions and skills learned are helping the participants and any other potential issues that they may be having with themselves or the program.

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

Since people with SMHC often will not voluntarily involve themselves in a new hobby or social situation, this program assists them in going outside of their comfort zone to become more connected to the outside world.

“It has helped me to reach out and connect with other people. I love the program. It is like a dream come true. I am learning new things about myself and others.”

“It’s a wonderful way to get out of isolation and start meeting new friends.”
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.

“The program helps me to be a little more confident. The friendships I have now are firmer since starting this program.”

“The program has taught me that I deserve to be loved.”
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
Peer support is a broad category of help provided by people who have a problem similar to the person they are helping.

Mutual support - including the sharing of experiential knowledge and skills and social learning - plays an invaluable role in recovery. Peers encourage and engage other peers in recovery and provide each other with a sense of belonging, supportive relationships, valuing roles, and community.
Tools and Innovation in IML: Peer Support (Evidence Based Practice)

- A Peer Support Specialist, often referred to simply as a “Peer,” is an occupational title for a person who has personal experience with a mental health and/or substance use problem, and is willing to talk about their experience in order to help others trying to recover from these or similar problems.

- CPS’ receive in-depth training on the concepts of recovery and how to utilize their own journey of recovery to assist others.
Tools and Innovation in IML: Peer Support (Evidence Based Practice)

Peer support is an evidence-based practice for the treatment of mental illness. Both quantitative and qualitative evidence indicate that peer support:

- Lowers the overall cost of mental health services by reducing re-hospitalization rates and days spent in inpatient services, increasing the use of outpatient services
- Improves quality of life
- Increases patient engagement and self-management
- Increases whole health
Tools and Innovation in IML: Peer Support (Evidence Based Practice)

- During the Deinstitutionalization Period, thousands of people that were being held in hospitals and asylums, were released into the community.
- The funds that had been spent on those institutions did not follow them into those communities.
- Communities were unable to provide care and often did not want the Mental Health Consumers living in their towns and cities.
Tools and Innovation in IML: Peer Support (Evidence Based Practice)

- In the late 70’s and early 80’s the idea of peer provided supports and services was born
- Awareness of the violation of civil rights and social justice accelerated change
- People began to talk about the need for peer involvement and empowerment within the mental health system
Tools and Innovation in IML: Peer Support (Evidence Based Practice)

Peer Support is critical in IML because peer-provided services increase:

- The ease of engagement with people
- The likelihood that people will fully participate in services
- The amounts of time that people stay in services for
Tools and Innovation in IML: Peer Support (Evidence Based Practice)

Peer Support is critical in IML because:

- As Peers, Life Coaches build trust
- Peers understand. They’ve been there
- Equality of the Relationship
- Information and experiences are freely exchanged
- Both parties benefit from each other’s strength and hope
Tools and Innovation in IML: Self-Directed Care (Emerging Best Practice)

- Self-Directed Care provides an opportunity for individuals living with a psychiatric condition to assess their own needs, determine how and by whom those needs should be met, and manage the funds to purchase those services.

- In Self-Directed Care the funds follow the person.
Self-Directed Care programs hinge on the belief that individuals are capable of choosing services and making purchases that will help them begin or remain on the road to recovery and to develop or regain a life of meaningful, productive activity.
The self-directed care movement is a natural outgrowth of the principles of self-determination. Self-determination refers to the right of individuals to have full power over their own lives, regardless of presence of illness or disability.

It encompasses concepts such as free will, civil rights and human rights, freedom of choice, independence, personal agency, and individual responsibility.
Tools and Innovation in IML: Self-Directed Care (Emerging Best Practice)

- The first self-directed care programs began in 1996 with the Cash & Counseling Medicaid Program for older adults.

- Cash and Counseling, now called Participant Direction, is an approach to long-term care personal assistance services in which the government gives people cash allowances to pay for the services and goods they feel would best meet their personal care needs and counseling about managing their services.
In 2001, Florida launched an innovative new program for all adults receiving public mental health services, Florida Self-Directed Care (FSDC).

This program allowed individuals to utilize the full amount of funds allocated on a per capita basis for mental health services. Each person determined their own recovery goals, the services and supports they needed to achieve them, and purchased those goods and services at places of their choice.
Self-Directed Care is critical in IML because:

- It has an underlying philosophy of self-determination, which in the mental health system refers to individuals’ rights to direct their own services, to make the decisions concerning their health and well being (with help from others of their choice, if desired), to be free from involuntary treatment, and to have meaningful roles in the design, delivery, and evaluation of services and supports.

-“Self-Determination Framework for People with Psychiatric Disabilities”
Tools and Innovation in IML: Self-Directed Care (Emerging Best Practice)

Self-Directed Care is critical in IML because:

- The ultimate goal of SDC programs is to give participants the opportunity to design and travel a personalized road to recovery free so that they can return to a productive lifestyle of what they choose to define it.

- People at all levels of recovery can benefit from SSDC.
Tools and Innovation in IML: Self-Directed Care (Emerging Best Practice)

Through Self-Directed Care, IML uniquely provides:

- Opportunities to practice newly learned skills in a safe and non-judgmental environment with feedback from Life Coach
- Recipients of services the chance to determine the skills they feel are important to them
- Financial support to participate in activities they would not otherwise be able to afford
- Creative ways to increase self-esteem and self-worth improving overall functioning with networks that include supportive and sustainable relationships that will increase their quality of life
Tools and Innovation in IML: Self-Directed Care (Emerging Best Practice)

Self-Directed Care is incorporated in IML as each participant was able to:

- Select their own Life Coach
- Determine their own goals
- Identify which skills were most important to them
- Establish their person-centered action plan
- Create and control their social budget
- Determine the location for meeting with their Life Coach
Tools and Innovation in IML: Psychiatric Rehabilitation (Evidence Based Practice)

A person-centered and strength-based approach to help individuals with persistent and serious psychiatric disorders to develop the emotional, social and intellectual skills needed to live, learn and work in the community with the least amount of professional support and increase their capacity to be successful and satisfied in the environments of their choice.
Psychiatric Rehabilitation emerged in response to the de-institutionalization period as the thousands of people newly released into the community were now in need of a treatment approach that supported and facilitated daily functioning and social interaction.

The term “psychosocial rehabilitation” is sometimes used interchangeably with psychiatric rehabilitation.
The expansion of peer roles in psychiatric rehabilitation has at least five attributes:

1. A deliberate expansion of a peer’s role beyond that of a user or recipient to include helping and support behaviors and activities.

2. An empowerment of the peer role by recognizing that peers can offer resources that traditional professionals either cannot offer or choose not to offer.
The expansion of peer roles in psychiatric rehabilitation has at least five attributes:

3. Expansion of what is meant by credentials to legitimize the understanding, knowledge, skills, attitudes and motivations peers have gained through their encounters with service systems and their experience a mental health clients

4. A view that some kinds of situations and roles, such as outreach, can be best fulfilled or led by providers who are themselves recipients of mental health services
The expansion of peer roles in psychiatric rehabilitation has at least five attributes:

5. A perspective that the provision of help not only assists a user or recipient, but can also create tangible benefits for the helper whose identity can be strengthened by helping another person in need.
Tools and Innovation in IML: Psychiatric Rehabilitation (Evidence Based Practice)

Psychiatric Rehabilitation is incorporated in IML as it aims to achieve:

- **Person Orientation** - Focus on the human being as a whole rather than an illness
- **Functioning** - How the person performs in everyday activities
- **Support** - Assistance is provided for as long as it is needed or wanted
Tools and Innovation in IML: Psychiatric Rehabilitation (Evidence Based Practice)

Psychiatric Rehabilitation is incorporated in IML as it aims to achieve:

- **Environmental Specificity** - Tailored to the individual’s specific environment (where they live, learn, work, socialize, etc.)
- **Involvement** - Include individuals as full partners in all aspects of rehabilitation
- **Choice** - Focus on the person’s preferences throughout the process
Tools and Innovation in IML:
Psychiatric Rehabilitation (Evidence Based Practice)

Psychiatric Rehabilitation is incorporated in IML as it aims to achieve:

- **Outcome Orientation** - evaluate rehabilitation in terms of its impact on outcomes
- **Growth Potential** - Focus on improvement in a persons success and personal satisfaction regardless of the person’s current difficulties
Tools and Innovation in IML: Life Coaching

The International Coach Federation (ICF) defines coaching as partnering with clients in a thought-provoking and creative process that inspires them to maximize their potential. Coaches honor the client as the expert in his or her life and work and believe every client is creative, resourceful and whole.

Coaching focuses on setting goals, creating outcomes and managing personal change.
Tools and Innovation in IML: Life Coaching

- The metaphor of the term “life coaching” developed from the practice of sports coaching. From about the 1830’s, a "coach" was any form of tutor.
- According to Merriam and Brockett (1997), professionalization of a discipline is demonstrated by the rise of professional associations, literature and graduate study.
- The emergence of professional coaching associations, training programs and publications started in the 1990’s and Life Coaching began to be recognized as a distinct profession.
Tools and Innovation in IML: Life Coaching

Life Coaching is incorporated in IML as Coaches:

- Guide participants to discover their own answers
- Help identify challenges and work in partnership to turn them into victories
- Challenge thought/behavior patterns
- Provide accountability
- Empower participants
- Assist with intensive goal setting and action planning
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

- “Traditional approaches such as medications, hospitalization, and dynamic psychotherapy have had limited effectiveness when applied to the socialization and work aspects of individuals with psychiatric disabilities” (Chan et al., 1998)

- IML provides one-on-one skill support and emphasizes that self-direction is not just for those who are “doing well”.

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

- 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 MHA, Janssen, and Alkermes 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: Part 2

Part 3 of this webinar series will take place at 2PM EST (11AM PT) on December 19, 2016

Thank You & Stay Tuned
Defeating Isolation and Social Exclusion Through Peer Empowerment

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

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