Defeating Isolation and Social Exclusion Through Peer Empowerment: Part 1

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.
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 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.

- Some participants also specifically concentrated on making friends outside of the mental health community. They stated that this was important to them because it helped them to take their focus off of their illness and turn it to what they felt was more positive in their lives.
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.

- Social functioning impairments seem to be evident at all stages of the illness. Data shows that these difficulties may even predate any signs of illness, often by many years. (Hooley J.M., 2010)

- “The impairments in social functioning that influence the lives of patients with schizophrenia are well captured in one simple observation. The majority of people with this disorder do not marry. Compared with people in the general population, patients with schizophrenia are more than six times more likely to remain unmarried.” (MacCabe, J. H., Koupil, I. a & Leon, D.A., 2009)
Social Connection Fits Into The Overall Goal and Journey of Recovery

- 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.

- 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.
While many programs attempt to provide people with social skills training, most have very limited success in really connecting people to friends and community. The It’s My Life Program is designed to fill that gap that exists in current systems or “treatment as usual”.

COMMUNITY MENTAL HEALTH CENTER

Presents:

Spaghetti Night

Friday, February 30, 2016
7-9 PM in the Conference Room
Contact: Imma Hungary to sign up
“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”.
IML is Unique

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
IML’s Process: Overview

- Life Coach Training
- Recruitment
- Forming Partnership
- Skill Building
- Outings
- Evaluation Techniques
- Results
Who’s Who in IML: Program Director

Role Includes:

- Providing supervision for Peer Life Coach Team - Supervision should include issues of job role clarification, performance, confidentiality, disclosure, working with other staff, boundaries and others as they arise.

- Providing support for Peer Life Coaches - Having appropriate support available is critical in peer support.

- Approving participants’ monthly spending plans - This includes verifying the social goals chosen by the Participant, assuring that the action/spending plans relate directly to the accepted social goals.
Who’s Who in IML: **Peer Life Coach**

**Role Includes:**

- Assisting participants in assessing what their goals are, completing their monthly social budget and action planning
- Conducting exercises to facilitate the accomplishment of goals; These various social skills, will strengthen the participant’s interaction with self and others.
- Serving as a role model of recovery and positive social interaction while accompanying participants to social activities; As time goes by Coaches begin to gradually pull away putting more responsibility on the participants.
- Encouraging participants to socialize with others; Coaches help to maintain current friendships and gain new friendships through various resources.
Who’s Who in IML: Peer Life Coach

Peer Life Coaches provide assistance and new social-life skills in several different areas, including:

- Helping participants with identifying areas of interest
- Collaborating in decision making with the participants
- Budgeting a spending account and attending social activities
- Assisting in building community inclusion
- Helping form and enhance healthy friendships and intimate relationships
- Coaching and feedback regarding progress
- Building connections to employment/volunteerism if desired.
Who’s Who in IML: Participant

Eligibility Requirements:

- Need for services is determined by completion of Personal Outcome Measures (POM) interview
- At least 18 years of age*
- Competent and able to give informed consent
- Able to manage personal finances, establish goals and action plans
- Willing to adhere to all agreed upon Participant Responsibilities
  1. Completion of POM interviews
  2. Regular meetings with their Peer Life Coach
  3. Weekly completion of Guided Journal
  4. Proper use and reporting of Social Spending Budget
IML’s Process: Peer Life Coach Training
Peer Life Coach Training

- Peer Support
- Self-Directed Care
- Psychiatric Rehabilitation
- Life Coaching
- Motivational Interviewing
Peer Life Coach Training: Peer Support

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.
Peer Life Coach Training: Peer Support

Core Components:
- Privacy and Confidentiality
- Ethics and Boundaries
- Mutuality
- Shared Decision-Making
- Effective Listening
Peer Life Coach Training: Peer Support

Core Components:

- 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
Peer Life Coach Training: Self-Directed Care

- 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.
Peer Life Coach Training: Self-Directed Care

Core Components:
- Self-Determination
- Civil and Human Rights
- Personal Agency
- Individual Responsibility
- Dignity of Risk
Peer Life Coach Training: Self-Directed Care

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
Peer Life Coach Training: Psychiatric Rehabilitation

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.
Peer Life Coach Training: Psychiatric Rehabilitation

Core Components:

- Emphasizes that recovery is possible and highly probable
- Person-centered
- Strengths based
- Recovery model vs. Medical model
Peer Life Coach Training: Life Coaching

Partnering with clients in a thought-provoking and creative process that inspires them to maximize their potential. This process helps people dramatically improve their outlook on their future, while improving their leadership skills and unlocking their potential.
Peer Life Coach Training: Life Coaching

Core Components:

- 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
- Intensive goal setting
- Action planning
Peer Life Coach Training: Motivational Interviewing

A person-centered, goal-oriented approach for facilitating change through exploring and resolving ambivalence; An engaging and collaborative conversation style for strengthening a person’s own motivation and commitment to change
Peer Life Coach Training: Motivational Interviewing

- Main goal is that participants will be able to make choices that are:
  1. Fully informed
  2. Deeply thought out
  3. Internally motivated

- Frame is provided by the Stages of Change with acceptance and compassion at the heart of Motivational Interviewing
Peer Life Coach Training: Motivational Interviewing

- Conversation includes moving from Status Quo Talk to Change Talk which is two-fold and uses the acronym DARN CAT

- Part 1 is Preparatory:
  - Desire
  - Ability
  - Reasons
  - Need

- Part 2 is Mobilizing:
  - Commitment
  - Activation
  - Taking Steps
IML’s Process: Recruitment

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

- Local Behavioral Healthcare Centers
- Drop-In Centers
- Clubhouses
- Community Centers
- Libraries
- Any and Everywhere Peers are Found

MHA is Seeking Women, Living with Schizophrenia or Schizoaffective Disorder, to Participate in Our FREE Social Explorations Project.

Are You Interested In:
- Meeting and Making New Friends?
- Receiving Money to Fund Social Events or Activities of Your Choice?
- Feeling Comfortable in Cultivating Relationships in Your Community?

Then You Are Invited to Join MHA’s

It’s My Life ~ Social Explorations

This Opportunity Provides a FREE Personal Coach to Assist in Reaching Your Social Goals. Our Personal Coaches are Certified Peer Support Specialists, Trained in Professional Life Coaching. Get Connected and Have the Time of Your Life! Why Wait? Call us Now!

Please Contact:
Patrick Hendry OR Shavonne G. Carpenter
Program Director Head Peer Life Coach, CPRS
phendry@mentalhealthamerica.net spcarpenter@mentalhealthamerica.net
Or Call him @ (703) 489-5742 Or Call her @ (703) 946-0529
Recruitment

Eligibility Requirements:

- Need for services is determined by completion of Personal Outcome Measures (POM) interview
- At least 18 years of age*
- Competent and able to give informed consent
- Able to manage personal finances, establish goals and action plans
- Willing to adhere to all agreed upon Participant Responsibilities
IML’s Process: Forming Partnership
Forming of Partnership: Getting Acquainted

- Coaches’ Bios are shared (in advance whenever possible)
- Participants meet all available Coaches to determine their level of “peer-ness” and compatibility; who they could relate to most
- Each participant selects their own coach
- Trust and solidarity are built through strategic self-disclosure, empathy, honesty and authenticity
Forming of Partnership: Explanation of the Program

- Participation is voluntary
- Confidentiality (HIPAA)
- Professional Boundaries
- Structure of visits with the Coach
- Appropriate use of the $60 Social Stipend and requirements for keeping receipts
- Phasing-Out process
Forming of Partnership: Explanation of the Program

- Participants receive a monthly allowance of $60.00 to be spent on advancing toward the three (3) social goals that will be 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.
Participants receive their handbook that includes everything they will need for the program:

- Enrollment agreement
- Guided Journal
- Various Forms
- Worksheets/Handouts
Forming of Partnership: Goal Setting

- Evaluate Participant’s feelings about current social standing
- Assess hobbies, interests and community involvement and accessibility to them
- Action Planning and IMPACT
- Create monthly Social Spending Plan
Skill Building

- Communication
- Emotion Regulation
- Effective Listening
- Self-Care
- Personal Boundaries
- Various other skills as they are discovered and the Participant feels they are necessary for positive social interaction
IML’s Process: Outings
Outings: Examples

Monuments & Museums

Art Classes

Swimming Classes

Theatre

Meet-up Groups

Peer Support Groups

Baking Classes
Outings

Participant & Coach

Coach accompanies Participant to event or activity and initially provides transportation if needed

Participant, Coach & Friend

Coach serves as a role model of recovery and positive social interaction
Coach may take Participant to stores to obtain needed materials for upcoming social events or activities

Participant & Friend

Participant applies acquired skills to become more independent in social interactions, thereby reducing their need for the coach and the coach gradually begins to pull away
Outings: Staying Engaged

Ensuring ongoing growth is essential to keeping participants engaged in the program. As participants learned new skills, their coach challenged them to first practice with the coach and eventually be able to use them on their own in social settings. Person-centered activities encouraged social interaction.
IML’s Process: Evaluation Techniques

- 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.
Evaluation Techniques: Personal Outcome Measures

- Developed by the Council for Quality & Leadership (http://www.c-q-l.org/the-cql-difference/personal-outcome-measures)
- IML focuses on 13 of the 21 quality of life indicators
- Interviews completed with each participant at least 3 times:
  1. Eligibility Determination
  2. Mid-point progress check
  3. Closing assessment
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.
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
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.
IML’s Process: Results

- Life Coach Training
- Recruitment
- Forming Partnership
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## Results: Personal Outcome Measures

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*
Results: Personal Outcome Measures

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*
Results: Guided Journals

- From the journal entries it was observed that the participants’ chosen activities often seemed to increase their overall self-confidence.

- 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.

- When they realize that they are more than capable of learning new skills and responding appropriately to social stimuli, they have a boost in self-confidence.
Results: Guided Journals

A direct result of participants being in control of their program and actively improving their social networks has been that they are learning about themselves which, in turn, provides them the opportunity to better themselves. For example, one participant went out to restaurants with different friends each week of her journaling. Each week, she would write about what she enjoyed and what she would like to do differently the next time. As the journals progress, it is evident that she is learning from mistakes and becoming much more comfortable engaging in appropriate restaurant conversation. By about the tenth week of journaling, she wrote,

“\textit{I was able to have a free flowing conversation that was effortless and was able to relax \\ & enjoy myself.}”
Results: Hospitalization Rates

- 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.
Results: Satisfaction Surveys

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

<table>
<thead>
<tr>
<th>Statement</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>
IML’s Process: Overview

- Life Coach Training
- Recruitment
- Forming Partnership
- Skill Building
- Outings
- Evaluation Techniques
- Results
Insights from the IML Team

- Loneliness and social exclusion destroy health and happiness. Research has shown that the lack of connectedness to friends and community worsens psychiatric problems and leads to chronic illness and early mortality. In surveys conducted, with people living with severe psychiatric disorders, asking what factors contributed most to their recovery, the number one answer is some variation on “having at least one person who believes in me, having at least one friend”.

- It’s My Life is an innovative, fun, supportive, and effective tool for building relationships in the community and discovering meaningful and productive activities.
Insights from the IML Team

- Self-directed care is essentially individual-based. It was interesting to find that participants often inquired what others were doing in the program and requested group activities. In response, we held three gatherings in the community and invited all program participants. The fourth gathering was actually organized and hosted by one of the participants.

- All of the participants have in some way maintained or improved upon the growth they achieved while in the program. One has become a Peer Support Specialist, several have returned to work or school, and others continue to set and pursue new goals involving their recovery.
Insights from the IML Team

- Working with one person there in particular was really hard. She wasn't getting any other services. I took her to ESL Classes and got her hooked up with a gym, but she really needed more help than what I could give her. She was living in such poverty and I remember, she didn't even have her own bed to sleep in. The financial support from the program was life changing for her.

- What I gained was knowing some really interesting people. I became friends with some of them. It was gratifying to see all of our people grow and change. I saw the success in their eyes when they reached some of their goals.
In the Words of Program Participants:

“I was deprived of the opportunity to eat in a restaurant for almost 13 years. So this program is like a revival to me.”

“[This program] has a positive impact on my life. It gives me hope. This is one of the best things that has happened to me. I will continue to move forward.”

“This was a really nice program. I enjoyed the money to buy beads to make jewelry for my friend. It is nice to have money to spend on my friends.”
In the Words of Program Participants:

“Confucius said, ‘I do, therefore, I understand.’ This was a program of doing and understanding. I have learned about small talk and am now a bit more assertive.”

“I am more confident to speak with people that I don’t know. I’ll introduce myself and talk with them. I used to wait for people to come to me. Now I start the conversation.”
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
- The IML Training Manual, Participant Handbook and Handouts
- Peer Support Specialist(s)
- Program Director
- Community Resources
- 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

Mental Health America’s experienced Peer Life Coaches are available for individual or group training in-person, by phone or video calls.
Would like to thank

Mental Health America

Would like to thank

Janssen

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 1

Part 2 of this webinar series will take place at 2PM EST (11AM PT) on December 9, 2016

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

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

For Additional Information Please Contact:

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