



Here in Our Club **Mona Wasow**

School of Social Work, University of Wisconsin Madison, USA

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Corresponding author: Mona Wasow

Commentary

Some years ago author read a book that profoundly influenced me: *Tell Them Who I Am*, by Elliot Liebow¹. This book was about women living in shelters for the homeless. As Liebow said in the preface: "People are homeless not because they are mentally ill, drugs users, or thieves, but because they do not have a place to live."

In addition to the influence of this book, author am so struck by our culture that refers to someone as "a schizophrenic," rather than by that person's name. If your aunt Tillie has cancer, you do *not* refer to her as "a cancer." She is "Aunt Tillie, and she has cancer." My son is a kind, bright man, 58 years old, who is deeply loved by his family. He makes beautiful pottery, and is a gifted musician who plays with me in a bluegrass band. He loves the wilderness and...many other things. We call him "David." Our culture calls him "a schizophrenic."

All of this inspired me to interview members of a club house in our city, called "Off the Square Club" (OTSC). This is a consumer staffed, daytime Drop-In-Center for adults living with mental illnesses, some of whom are homeless. It is operated by Lutheran Social Services of Wisconsin and Upper Michigan. The Club served 167 members in 2012.

To become members of OTSC, applicants must provide verification of a mental illness diagnosis. Many members are homeless and living in various locations or one of the shelters for homeless people. Staff members at OTSC strive to create a warm, accepting environment for all who attend. "OTSC is a place for members to receive many kinds of support. Community resources counseling, emotional support, crisis intervention, and some vocational opportunities are available to any member who requests it. OTSC's foundation, however, is the provision of a stigma free, safe daytime shelter where members can rest, eat two meals, and socialize Monday through Friday. OTSC provides a safe context for members to socialize with other members, and to escape the isolation and harmful relationships that many people with chronic forms of mental illness experience. Members also have the opportunity to experience positive regard and empathy by developing a working relationship with staff. These relationships can be critical aspects of a recovery journey, and may even save lives"².

As a member of their advisory board, and as a mother of one of

✉ mwasow@wisc.edu

School of Social Work, University of Wisconsin, Madison, USA.

Tel: +1 608-263-3660

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their attendees, author decided to interview club members who were willing to tell me a bit about themselves.

Author introduced myself to members, telling them I was interested in knowing something about who they were. Author said: "Author work on the OTSC Advisory Board, and am very interested in the people who come here: who you are, what is important to you in your life, what your hopes and dreams are... Just anything you care to tell me about yourself! I'll take a few notes while you are talking to me, and when we are done talking, I'll read them back to you. Then you can see if author got it right; and change anything you want; or add something... whatever."

The following are some of their stories. Keep in mind that these are all club members who *agreed* to be interviewed, and mostly seemed to enjoy the process. There were a few individuals who declined being interviewed. So there is a built in bias: the people who wanted to talk. Author wish to knew more about those who declined!

Todd Winstrom is the present director of OTSC, starting his work there the summer of 2014. Todd had been to law school, so author was surprised that instead of going into some kind of law practice, he took on the directorship of OTSC. Author asked Todd about this, and he said, "Serious mental illness (SMI) touched my family. My dad had big SMI problems and ended up committing suicide." "Hey," he said, "I've seen a therapist, have taken meds, I'm a consumer too. It's time I came out of the closet."

Todd talked about wanting to be a stigma buster. He feels that OTSC is unique and fills a notch no other program fills. "The club can be for each person, what they need it to be." He further

¹Penguin Books, 1993. 375 Hudson St., N.Y., N.Y. 10014. U.S.A.

²Notes given to the Advisory Board of OTSC, 2014.

explained, some folks come just to eat lunch, others come to see people, or to watch TV, to find a doctor, to get help in finding a place to live, to shoot pool, and so on. "We cover the whole broad spectrum, and our flexibility is so special." Todd's face lit up as he explained this to me.

Homelessness is a big issue here, and many people do not even have access to a telephone. OTSC provides telephone access. But our biggest power is that of peer support.

Todd feels strongly that SMI professionals are seeing that their work is very important, and that it is possible for mentally ill people to get their lives back. "We need to have faith in them, and in ourselves," he said.

Todd also talked about how some of the treatments in the past were harmful. "The vision of getting better-of being able to *do* things-is what recovery is about," he said. When I mentioned the stigma and prejudice about SMI's in our culture, Todd said, "Yes, external stigma is awful, but *internal* stigma is even worse."

Linda Cole is the Program Manager of OTSC, as well as six other Day Centers for people with SMI's. She worked for twenty years in a recovery center. She feels that for many of our members, it is their family, as they have little or no contact with their families of origin. "They can build positive memories here -this place normalizes their lives."

How fortunate OTSC is to have Todd Winstrom and Linda Cole working for them.

Robert Williams is a 53 year-old man who was quite willing to be interviewed, and to have his name in print. Talking with Robert was a moving experience for me. He's had a very hard life, but to use his own words: "Life has obstacles... but you can accomplish things. Author believe in hard work, and to be responsible for all I say and do."

Robert was born in Madison. Both his parents had a SMI: Bipolar Depression for his father, and Schizophrenia for his mother. When he was two years old his parents divorced. Then he was in foster care for a short period.

Robert was the youngest of eight children. He did a lot of moving around to live with different relatives. From age 14-16 he lived on a farm in Wisconsin. "Author was always taught to work hard," he said.

He talked about being very shy as a child and teenager. "Author went to a prom my junior year in high school, and didn't even get a kiss!" he told me with a grin. He graduated from high school at the age of 18, and then went to work for a co-op. Then he went on to Madison Area Technical College (MATC). It is impressive that he did this, given little encouragement to do so from any family member.

Alas, Robert was doing a lot of drinking and smoking pot, so he did not earn class credit. He also had a close friend who died of AIDS at this time, and that was very painful for him.

After leaving MATC, Robert went to Wyoming where he got a blue collar job for the summer. Then he joined the Navy, where he did six months. "That was good," he told me. (Author do not know why it was only six months).

When he returned to Madison, he was homeless and lived for a while at Porchlight, a shelter for people who are homeless. He then was able to get on Social Security. His next move was to a shelter called Tellurian, where he lived for four years.

At the end of our interview author said to Robert, "I'm amazed at how you survived all this." He seemed so pleased that I said this, and responded, "I'd like to be in a good family, I do like people."

A few men were very circumspect. David, age 57, only offered "OTSC is a place to come; somewhere to eat; a place to make friends." When I asked him to tell me about his life, he just shook his head.

Al B. is a homeless man, who has schizophrenia. For him, right now, the most important thing is finding housing. He says: "I don't like male roommates; they are too messy."

Al did go to the University of Wisconsin, but did not say for how long. He would like to write "a book of poetry and essays." He tells me he is a good cook, and a good hard worker. At the moment, however, he has a bad back, and cannot hold a full time job.

Andrew is 45 years old, and tells me his diagnosis is "schizoaffective disorder" but does not believe the diagnosis is correct. He thinks he has "mild anxiety."

Andrew says that he had a lot of jobs in the past, and that he used to be a lawyer. He said he reflected on his thoughts and feelings every day, and writes in a journal he keeps. He uses the internet a lot.

When author asked him for more information about his life, he said, "author was married for ten years. I'm proud of my philosophy groups that author belong to. Now author get along with my dad, and author happy about that."

He ended his interview by saying, "I've gotten off most of my meds, and that's good." Andrew has been a member of OTSC since 1997, and likes to help out at the club.

A 65 year-old woman I interviewed did not want me to use her name. She has three grown children and one grandchild. This lady was a Vietnam veteran, and she played baseball in the Army. At that time, she said she had a lot of friends. She also attended the University of Wisconsin, and was an art major. She then worked in Special Education. Around this time she got diagnosed with depression; then with manic-depression. "Author always had ups and downs as a kid," she said. She said that "911 pushed me over the edge." She dropped away from her friends then, and was feeling so depressed that "she didn't feel worthy." She was "comatose and very angry" when she first came to OTSC about eight years ago. Now she is the kitchen manager at OTSC, a paid job. "Author now feeling better, and seeing my old friends." She is also taking anti-depressant medication, and says "they help me a lot."

Robert is 59 years old, has schizophrenia, and has post-traumatic stress disorder. He has had a difficult life, including a short prison term. He does not want me to use his last name. He told me he grew up in Milwaukee, and had a "tough childhood." He also had a hard time in school, though eventually got his G.E.D. Robert was in the Army "for a while," worked on and off after he got out

of the Army, and had “some schooling.” (He was not clear about the schooling). He has a brother in Madison, and some nieces and nephews. He came to live in Madison in 1998 and has been a member of OTSC for “about 10 years.” He has been homeless for a number of years, and was in jail a “short prison term: for felony/burglary.” When he was unemployed he went to The Veteran Association and said they were very helpful. The V.A. connected him to drug treatment counseling, helped him get a job, and “some other benefits.” Robert talked about how the staff at OTSC has been very helpful for him: “My biggest resource to get myself back on track is talking to other veterans; and to staff at OTSC.”

Bart is a lovely 59 year-old man who is the “Human Resource Specialist” for OTSC. He has had this position for seven years at OTSC, and has been involved with running a boarding house for a community PACT³ program at the same time. It was through his involvement with the Boarding House that he first became interested in OTSC. Between working at the Boarding House and OTSC, Bart has put in 23 years of work. He gets room and board and \$11.00 an hour for his work at OTSC.

Bart grew up in Wautoma and several other Wisconsin cities. In fact, he lived in eight different places by age 17. That must have been hard.

He has a Master’s Degree in Hebrew and Semitic Studies. He wanted to be able to read the Hebrew Scriptures, and continues to do so in the present. “Author am looking for the spirituality in these scriptures,” he told me. He was ordained in 1983, and worked for three years as a minister. After these years as a minister, Bart decided to leave that profession. “Author wasn’t cut out of the clerical cloth,” he said. For a few years he became an apartment painter, lost that job, and started his own business, which he ran for 15 years, from 1992-2007. In 2007, he applied for the OTSC job as a “Human Services Specialist.”

Bart has had experience with mental illness himself. “Being able to help people with mental illnesses helps me with my own stress,” he said. Then he smiled and added: “Misery loves company.”

What a plucky fellow-what a lovely man Bart is. Interviewing him was a moving experience for me.

As you can see from these few interviews, all of these people are so much more than their diagnoses.

Some Further Thoughts

In my introduction I mentioned Elliot Liebow’s book, *Tell Them Who I Am*. One of the points he made certainly reflected by findings: “What sets these homeless women apart is that, sane or crazy or physically disabled, they are all engaged in a titanic struggle to remain human in an unremittingly dehumanizing environment. Most of them are successful”⁴.

Liebow also wrote about the boredom that most people with mental illness and/or homelessness had to deal with. “Along with perennial fatigue, boredom was one of the great trials of homelessness”⁵. Indeed, in my hours spent interviewing people at OTSC, author was struck by the boredom many people seemed

to be experiencing. Many folks sat in front of the T.V. set, looking quite bored. Some spent a lot of their time outside smoking; others lay asleep on the couches and chairs; or just sitting in silence waiting for lunch time.

But Liebow also wrote about the courage of these people. “As author worked closely with people who had the illness, author became aware of their courage, of their struggle to hold on to the fragility of themselves⁶. He goes on to say that as long as serious mental illnesses are treated like some evil and frightening nemesis, and not just as illnesses, our culture will continue to spurn those who are so afflicted. Indeed, cultures all over the world tend to treat people with SMI’s as outcasts of society. That large numbers of people with SMI’s are living on the streets, or worse, in jails, because there is nowhere else for them to go, is morally indefensible. “We must stop blaming the poor for being poor and the homeless for being homeless”⁷.

In 1999, Mitchell Dunier wrote a book about homelessness⁸. When he asked a homeless man why he was urinating on the streets instead of using a public toilet, the man responded:

“It is too nast. The toilet bowl has no seat on it. There’s shit all around it. Now, who’s going to sit their ass where there is shit all around the fucking rim?”

Author put this quotation in, not to be vulgar or dramatic, but rather to reflect a reaction author think most of us would have. Is the man urinating in the streets because of a SMI, or homelessness, or because of the condition of the public toilet?

In 2014 Anne Saker wrote an article for the *New York Times* called, “Stories as a Window into Schizophrenia”⁹. In talking with people who had SMI’s, she found that of the many injuries inflicted upon these people, the greatest seemed to be the pain of being forgotten. “One thing author learned was just as soon as you mentioned the word [schizophrenia], people stopped seeing the person. They just saw the diagnosis and a collection of symptoms.”

Anne Saker asked the people she interviewed, “What is it like to be you?” Many interviewees told her that no one had ever asked them about their lives. They also talked about being very lonely.

The quality of life of people struggling with SMI’s remains so inadequate, and mostly segregated from non-SMI people. “Their courage, resilience, and yes, their strengths in the face of a mean spirited disease and an often unresponsive and oppressive society have taught us more about being human than anything else”¹⁰.

In recent years some excellent books have been written about SMI’s, the people who have such illnesses, their families, and the social services trying to be helpful. One of my favorite books was written by an Australian woman, Anne Deveson, called *Tell Me I’m Here*¹¹. She writes about how SMI’s have been kept in the shadows, and that “Instead of rejection, we need acceptance. Instead of shame, we need love. Instead of despair, we need solid and unwavering support. It’s time to come out of the shadows

⁶Liebow, p. 224.

⁷*Sidewalk* by Mitchell Dunier Farrar, Straus, & Giroux. 1999.

⁸Dunier Farrar, Straus, & Giroux.

⁹Anne Saker, N.Y. Times, May 5, 2014.

¹⁰*The Strengths Model* by Charles A. Rapp, Oxford Univ. Press, 1998. p. xvi.

¹¹Anne Deveson, *Tell Me I’m Here*. Penguin Books, Australia, 1991. P. 261.

³PACT: Program of Assertive Community Treatment.

⁴Liebow, *Tell Them Who I Am*, p. 222.

⁵Liebow, p. 29.

and into the light.” (And this was written in 1991, 24 years ago. Not much has changed since then.)

When Deveson made a T.V. documentary on SMI’s in 1991, she said, “As author worked closely with people who had these illnesses, author became aware of their courage, of their struggle to hold on to the fragility of themselves.” This was exactly what author experienced while talking with club members of OTSC.

In conclusion

OTSC, founded in 1978, has provided 37 years of a wonderful, safe, caring environment for people who struggle with SMI’s, and in addition for some, homelessness. It is staffed

by “... compassionate, knowledgeable, and skilled individuals who use their personal mental illness (Peer Support) experience to offer hope and assist others in living full, well lives within the community”¹².

Interviewing a random sample of club members and staff was a deeply moving experience for me. This is my attempt to reinforce the fact that these individuals are just that, *individual human beings*. They cope valiantly with difficult illness, and go about their lives as best they can. OTSC is a wonderful club house where many folks can spend some meaningful time. Blessings on all of you.

¹²From notes describing OTSC by Lutheran Social Service.