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## Using Photovoice to Fight the Stigma of Mental Illness

*“We now recognize both the negative impact of the illness itself, as well as the second layer of trauma that comes from the stigma attached to the mental illness.”*

— Zlatka Rusinova, Senior Research Associate, Center for Psychiatric Rehabilitation

Over the past several decades people with psychiatric disabilities have increased their participation in employment, residential, and social environments. This increased participation is a welcome and positive trend, and a core concept of recovery-based rehabilitation. Yet as community participation has increased, the problem of stigma has moved to the forefront of recovery challenges, directly

impacting the lives of consumers, families, and caregivers.

Stigma experienced by persons with psychiatric disabilities presents a major barrier<sup>1</sup> to recovery. As part of the movement to confront stigma, the Center for Psychiatric Rehabilitation is using Photovoice, an innovative participatory research tool, to combat stigma in the lives of consumers.



*The drain calls to me because of all the hurtful things people have said to me over the decades about my mental illness. In sum, I have been told that I am a drain on the nation, a drain on society, and a drain on multiple individuals’ resources. Over the years, I have come to believe this, which has been a drain on me. Education about mental illness (and the effects of trauma) should be able to reach out to the general public, as well as healthcare professionals. Knowledge and understanding can be powerful weapons in combating stigma.*



*I have to cross this busy intersection every time I enter McLean Hospital grounds to see my psychiatrist. I often wonder what the people driving by think when they see a lone pedestrian enter through that gate, usually under cover of night. Am I just an inconsequential traffic hazard, to be disregarded and forgotten once my passage has been negotiated, or do I represent some darker and more foreboding form in their lives? I may never know their thoughts, but to me, the gate on the other side of that intersection represents a barrier which I once could not cross at will and part of my life I am now trying to put behind me. Ultimately, though, I resign myself to the premise that we are all just journeying, doing our best to get where we are going, whether it be across the street or down the road a piece. So I pause on the corner to let them pass, and, most of the time, they do the same for me.*

## Stigma and Persons with Psychiatric Disabilities

A growing body of knowledge demonstrates the negative impact of stigma on self-esteem, well-being, employment, housing, community integration, and social adaptation while the subjective experience of stigma is associated with avoidance of social interaction and increased depressive symptoms.<sup>2</sup> According to Zlatka Russinova, Senior Research Associate at the Center for Psychiatric Rehabilitation, “We now recognize both the negative impact of the illness itself as well as the second layer of trauma that comes from the stigma attached to the mental illness.” This secondary trauma experienced by people with psychiatric disabilities as a result of stigma impedes their recovery process beyond the factors typically associated with the disability.<sup>3</sup>

Stigmatizing attitudes have been found not only in the general population, but also among landlords and employers, mental health providers, family members, and even persons with mental illnesses.<sup>4</sup>

In addition, people diagnosed with mental illness often expect to be rejected, shunned, devalued, and discriminated against by others, and these expectations can affect their self-esteem, social interactions, mood, and anxiety level. Internalized stigma, often

described as self-stigma, can further affect behavior and performance.<sup>5</sup>

Stigma remains an enormous barrier to recovery and community participation, and, as a result, mental health programs have incorporated interventions—some focusing on helping consumers cope with stigma, others confronting stigma through advocacy and education. The “Photovoice Anti-Stigma Empowerment” psychoeducational intervention developed at the Center for Psychiatric Rehabilitation combines both approaches. Psychiatric rehabilitation assists people with psychiatric disabilities increase their participation in communities of choice in the service of assisting people to achieve recovery goals.

## A Difficult Challenge, A New Solution

Photovoice is an empowering tool that has been used in a variety of settings and among different constituencies, including communities of people with psychiatric disabilities. Photovoice puts cameras in the hands of individuals and asks them to produce statements made up of pictures and words that communicate their experience. This empowering tool enables people at the grassroots level without access to decision-makers to represent and define issues of concern, areas of strength, and targets for change—all of which are routinely defined by health specialists, policy makers, or professionals.

The original concept of Photovoice was developed by Professor Caroline Wang at the University of Michigan School of Public Health and Mary Ann Burris from the Ford Foundation. Since then, Photovoice has been used for research, education, social change, and the development of more healthful public policy. Women living in the villages of rural China, people residing in the homeless shelters of Ann Arbor, Michigan, and individuals struggling with a serious mental illness in Boston have all used Photovoice to amplify their vision and experience. This process emphasizes the knowledge of people with lived

experience as a vital source of expertise. The Center for Psychiatric Rehabilitation has chosen Photovoice to help people with psychiatric disabilities to identify and confront the experience of stigma in their lives.

## Using Photovoice

In 2005, the Center for Psychiatric Rehabilitation began using Photovoice in a Recovery Education Program class entitled “Picturing My Health.” This class engaged students using Photovoice to explore health and wellness issues as experienced by adults with psychiatric disabilities. Response was overwhelmingly favorable and Photovoice continues to be over-selected each semester in the Recovery Education Program. Following the success of “Picturing My Health,” eight other Photovoice classes have been offered, addressing the topics of recovery, spirituality, and stigma.

The Center’s Photovoice intervention regarding stigma proved to be a powerful intervention for the participants. Each member of the class was able to create photographs exposing the impact of stigma in their lives. The class met the goals of creating photographs with narratives that explored their lived experience and exhibiting their work to mental health providers and the public. In addition to the standard goals of Photovoice, the class brought about remarkable personal changes for the participants. After participating in the class, Catherine Imbasciati reported that, “Photovoice meant reaching out to try to talk to people to help people to understand—not just for me—but trying to turn my experience into a tool for other people to understand.” Students were able to increase their awareness of how internalized stigma served as a barrier to community participation. They also reported feeling stronger and more likely to address stigma in their worlds.

A curriculum consisting of a workbook and an instructor’s guide has been developed and piloted through several rounds of classes. The workbook leads students through the Photovoice process step-by-step, while the instructor’s guide provides

comprehensive instruction in leading Photovoice workshops—with a thorough understanding of the guide, an instructor may lead workshops with no other training. This curriculum will ensure the intervention may be easily delivered at outpatient mental health and rehabilitation settings as well as consumer-run programs and centers.

Recognizing the power of Photovoice in exploring stigma, the Center has embarked on a new project. Through funding from the National Institute on Disability and Rehabilitation Research (NIDRR) and the Center for Mental Health Services (CMHS), the Center is currently developing and pilot-testing a peer-run educational group intervention meant to foster mental health consumers’ competence in coping with stigma and discrimination. Focusing on increasing consumers’ awareness of stigma and discrimination while empowering them to cope with different types of stigma through adaptive coping strategies, the program will emphasize recovery. In two different settings, eighty individuals will be randomly assigned to either the Photovoice stigma intervention or to a wait list control group. The study will measure the efficacy of the intervention in terms of stigma coping skills, level of self-stigma, empowerment, self-efficacy, and depression. The Center is currently recruiting peers to be trained as instructors in the Photovoice

## Don’t Close the Doors on Me

*Often I am stigmatized because of the scars on my arms. People close the door before getting to know the true “inside” of me. Sometimes I feel the causes of the battle scars were easier to recover from than the cruelty from everyday people and the health care professionals judging me. They make an assumption that I am dangerous or scary without ever getting to know me. There are reasons I have these scars. It would be a perfect world if people did not judge one another because of someone being different, just because they did not have an understanding of the issue. Educating the everyday public and health care providers on why and how things like this happen will lessen the stigma. Understanding something usually takes away most of the mystery—people are not as afraid.*



The success of the Photovoice Anti-Stigma Empowerment class has been featured in a variety of public forums:

- A short documentary, "Beyond the Shadow of Stigma," aired on a local television station and was featured at the Center's "From Innovations to Practice" conference.
- Photovoice pieces from Anti-Stigma Empowerment classes were exhibited at a local art gallery as well as in the Center exhibition space.
- A display and training activity session formed part of the Center's "From Innovations to Practice" Conference.
- A full-day training institute in Photovoice Anti-Stigma Empowerment was held at USpra's annual conference.

class. Three trained peer instructors will provide the intervention to small groups of consumers.

Stigma is a real and negative factor in the lives of persons with psychiatric disabilities. Understanding stigma, eliminating stigma, and changing the way individuals experience stigma must be a key element in any recovery-oriented program.

Through Photovoice, consumers are empowered to reach a wide audience—potentially including many decision makers—utilizing a practical, delivery-oriented, low-cost intervention that does not require extensive training. As the use of Photovoice becomes more widespread, the insight of individuals with lived experience will help us leave behind misconceptions about the experience of psychiatric disability.

#### End Notes

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