

Combating Prejudice and Discrimination

through **PhotoVoice Empowerment**

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Second Edition

Boston University Center for Psychiatric Rehabilitation

Leader's Guide

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Companion Products

A workbook about group leadership skills:

Spaniol, L., McNamara, S., Gagne, C., & Forbess, R. (2009). *Group process guidelines for leading groups and classes*. Boston, MA: Boston University, Center for Psychiatric Rehabilitation. <https://cpr.bu.edu/store/curricula/group-process-guidelines/>.

A book with personal accounts about recovery and Photovoice examples:

McNamara, S. (Ed.). (2009). *Voices of recovery*. Boston, MA: Boston University, Center for Psychiatric Rehabilitation. <https://cpr.bu.edu/store/books/voices-of-recovery/>.

Posters: Looking Beyond the Label

A set of color posters documenting actual Photovoice work created by students who have completed the Combating Prejudice and Discrimination through Photovoice Empowerment class. The posters measure 24" x 30" and are available mounted or unmounted, as a complete set, or singly. These may be viewed on BU's Center for Psychiatric Rehabilitation website at <https://cpr.bu.edu/store/multimedia/photovoice-posters/>, and they may be ordered directly from the printer at: <http://www.colortekofboston.com/>.

A video: "Beyond the Shadow of Stigma"

The video is accessible online at: <https://cpr.bu.edu/resources/webcast/beyond-the-shadows-of-stigma/>

Table of Contents

	Pages
Introduction	
Prejudice, Discrimination, Ignorance, and Stigma	6
Background of Photovoice	7
Goals of Photovoice	8
The Photovoice Narrative	9
Photovoice at the Center for Psychiatric Rehabilitation	9
The Anti-Stigma Photovoice Curriculum	10
Cameras and Technology	11
Role of the Participants	12
Role of the Leaders	13
Engaging the Participants	14
Dealing with Challenging Behaviors in the Group	15
Exhibiting Our Photovoice Work	16
References and Resources	17
Sample Class/Group Outline	20
Class 1: Overview of the Photovoice Program	21
Purpose and Goals of the Photovoice Program	23
Exercise: How Do I See Myself?	24
Examples of Photovoice	25
Benefits of Photovoice	28
Photovoice Class Roles and Responsibilities	29
Class 2: Nature of Stigma: Ignorance, Prejudice, and Discrimination	32
Defining Ignorance, Prejudice, and Discrimination	33
Characteristics of Prejudice and Discrimination	34
Internalized Biases and Stereotypes	35
Exercise: Homo Stigmatus	36
Class 3 Stages and Process of Photovoice	40
Definition, Background, and Goals of Photovoice	41
Stages and Process of Photovoice	42
The Photo Mission and Ideas	43
Important Considerations for Photovoice Researchers	45
Instructions For Use of Cameras	46
Ethical and Safety Guidelines for Photovoice	46
Requesting Permission to Take Pictures	49
Photography Permission Form	50

Class 4	Power of Language and Stereotypes	52
	Thoughts and Reflections on the Photo Mission	53
	Viewing Pictures	54
	Importance of Language	55
	Exercises: Understanding Stereotypes	56
Class 5	Development of Photovoice Narratives	60
	Example of Photovoice	61
	Writing Photovoice Narratives using SHOWED	63
	Practice Writing Photovoice Narratives	65
	Writing Narratives for Your Own Pictures	66
Class 6	Coping with Ignorance, Prejudice, and Discrimination	69
	Defining Coping Strategies	70
	Strategies for Coping with Ignorance, Prejudice, and Discrimination	71
	Exercise: Coping with Ignorance, Prejudice, and Discrimination	74
Class 7	Identifying Strengths and Resources	77
	Exercise: My Personal Strengths	78
	Example of Photovoice	78
	Exercise: Homo Luminous	79
Class 8	Planning Photovoice Exhibits	82
	Finalizing our Photovoice Narratives	83
	Identifying Audiences for Photovoice Exhibits	84
	Targeting Special Audiences	84
Class 9	Integrating Strengths and Vulnerabilities	88
	Learning to Integrate Personal Strengths and Vulnerabilities	88
	Exercise: Homo Harmonius	88
	Planning our Photovoice Exhibit	91
Class 10	Celebrating Our Photovoice Work and Process	93
	Reviewing Our Photovoice Journey	94
	Exercise: How Do I See Myself?	95
	Taking Stock in Our Growth	96
	A Wish for the Future and Farewell!	97
Appendices	List of Appendices	98
	1. Technical Instructions for Implementation of the Program	99
	2. Ethical and Safety Guidelines for Photovoice	107
	3. Photography Permission Form	108

Introduction

Prejudice, Discrimination, Ignorance, and Stigma

Over the past several decades, people with psychiatric disabilities have increased their participation in vocational, educational, residential, and social environments. This increased participation and social inclusion is a welcomed and positive trend, and a core concept of recovery-oriented psychiatric treatment and rehabilitation. As community participation has increased, the problems of ignorance, prejudice, and discrimination have moved to the forefront of recovery challenges, directly impacting the lives of people in recovery, families, and caregivers.

Ignorance about mental illnesses, prejudicial attitudes, and discriminatory behaviors experienced by persons with psychiatric disabilities present a major barrier to recovery (Corrigan & Rao, 2012; New Freedom Commission on Mental Health, 2003; Thornicroft, Brohan, Rose, Sartorius, & Leese, 2009). As part of the effort to confront these negative attitudes and exclusionary behaviors, the Center for Psychiatric Rehabilitation at Boston University is using Photovoice, an innovative participatory research tool that has become a powerful instrument for social justice to expose and combat prejudicial attitudes and discriminatory behaviors in the lives of people who experience psychiatric disability.

A growing body of knowledge demonstrates the negative impact of stigma, prejudice, and discrimination on self-esteem, well-being, employment, housing, community integration, and social adaptation (Livingston & Boyd, 2010; Corrigan, Powell, & Rüsch, 2012; Yanos, Lysaker, & Roe, 2010; Brohan, Elgie, Sartorius, & Thornicroft, 2010; Wahl, 1999). According to Zlatka Russinova, Director of Research at our Center, “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.” (Mertl, 2007). This secondary trauma experienced by people with psychiatric disabilities as a result of ignorance, prejudice, and discrimination impedes their recovery process beyond the factors typically associated with the disability (Schulze & Angermeyer, 2003; Spaniol, Wewiorski, Gagne, & Anthony, 2002).

Prejudicial 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 (Parcesepe & Cabassa, 2013; Russinova et al., 2011; Wahl, 1999). 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 stereotypes from others, often described as self-stigma or internalized oppression, can further affect behavior and performance (Thornicroft et al., 2009).

Discrimination 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 prejudice and discrimination (Mittal, Sullivan, Chekuri, Allee, & Corrigan, 2012; Yanos, Lucksted, Drapalski, Roe, & Lysaker, 2015), others confronting prejudice and discrimination through advocacy and education (Corrigan, Morris, Michaels, Rafacz, & Rüsch, 2012). This Photovoice curriculum developed at our Center is a psychosocial intervention, which combines both coping and advocacy approaches.

Currently many writers and researchers use the overarching concept of stigma to describe society's ignorance about mental illnesses, and the negative attitudes and discriminatory behavior directed at people diagnosed with mental illnesses. Indeed professional publications, the mainstream media, research projects, training programs, etc. have used the word "stigma" in this traditional way.

Photovoice breaks with that tradition.

The Photovoice curriculum reviews with participants the term "stigma," as it has been used historically, and then turns them toward more accurate descriptors of what needs to be combated; namely, manifestations of ignorance, prejudice, and discrimination. The controversy about the concept of "stigma" can be summarized as follows:

- First and foremost, the word "stigma" is offensive to many people. The original meaning of the word stigma is a mark or stain of infamy, disgrace, or reproach. The mark of shame should not reside with people who have been diagnosed with mental illnesses, but perhaps on those who perpetuate ignorance, negative attitudes, and discriminatory practices.
- Our dear friend and colleague, the late Judi Chamberlin, believed that the concept of stigma is itself stigmatizing because it implies that there is something wrong with the person and that the word discrimination puts the onus on where it belongs, on the individuals and groups who are practicing discrimination. The concept of stigma focuses too much on the individual who is discriminated against and not enough on the societal attitudes and practices that need changing.
- Researchers and others have noted that the concept of stigma is inexact and that it has multiple meanings. Most research on stigma and mental illness has focused on attitudes, which has not produced models that suggest effective interventions to combat prejudice and discrimination. Focusing on the concept of stigma has separated the field of mental health from the mainstream of disability policy.

For these reasons, the curriculum uses the terms ignorance, prejudice, and discrimination, which are defined as follows: Ignorance is the lack of knowledge or misinformation about mental illness; prejudice refers to negative beliefs and attitudes; and discrimination refers to behaviors directed against people diagnosed with mental illnesses that deny them the rights, access, and opportunities that others may enjoy.

Background of Photovoice

The Photovoice concept was developed by Professor Caroline Wang at the University of Michigan School of Public Health and Mary Ann Burris from the Ford Foundation. Photovoice is a process that has been used for research, education, social change, and the development of more healthful public policy. It empowers people who may be marginalized in society and have little access to policy makers by giving them cameras and asking them to capture in pictures and words phenomena that matter to them. People, whose voices frequently go unheard and whose perspectives often are overlooked (such as from women living in the villages of rural China to people who reside in the homeless shelters of Ann Arbor, Michigan, to people struggling with a serious mental illness in Boston), have used Photovoice to articulate and amplify their vision and experiences. Photovoice values the

knowledge put forth by people living in a community or with a particular health condition as a vital source of expertise. Photovoice gives a voice to people at the grassroots level, enabling them to define and represent issues of concern to their communities, rather than leaving it to health specialists, policy makers, or professionals to do so on their behalf. By uniting the immediate impact of a photograph and the story that contextualizes and enhances it, Photovoice enables us to gain the possibility of perceiving the world from the viewpoint of the people who lead lives that are different from those traditionally in control of the means for imaging the world (Wang & Burris, 1997). Photovoice has evolved into a powerful empowerment strategy (Catalani & Minkler, 2010; Hergenrather, Rhodes, & Clark, 2006) that has been useful for many groups including Latinos and other marginalized people (Vaughn, Rojas-Guyler, & Howell, 2008).

Negative perceptions of people with mental illnesses often have resulted in their exclusion from mental health research, service planning, and community education efforts. Traditional research methods (both qualitative and quantitative) require people to be able read, write, or speak in settings that may not be comfortable or empowering or that fail to accommodate limitations that can accompany mental illness (i.e., difficulty communicating or focusing due to cognitive symptoms, social anxiety, paranoia, etc.). Using a camera places the power to represent the world in the hands of people living with a mental illness, freeing them from some of the constraints of other modes of communication, and allowing them to join in the process creating of knowledge and catalyzing change. Additionally, participating in Photovoice has personal value for the photographers, enabling them to see themselves, their lives, and their communities from new perspectives.

Through Photovoice, people with psychiatric disabilities 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.

As demonstrated from the images and narratives, Photovoice offers an innovative participatory strategy for including more people with mental illness in research, education, and advocacy projects. In the words of Dr. Martin Luther King, “Our lives begin to end the day we become silent about things that matter.” Through the power of the visual image, Photovoice offers an innovative way to break the silence that often surrounds the experience of mental illness.

Goals of Photovoice

Photovoice has 3 main goals:

1. To enable people to record and reflect their community’s strengths and concerns.
2. To promote critical dialogue and knowledge about personal and community issues through large and small group discussions of photographs.
3. To reach policy makers.

To these ends, the Photovoice process lays out multiple stages for defining the goals of a project, anticipating an audience, taking pictures and telling stories about them, evaluation,

and presentation. While Photovoice can be done on a more individual basis, one of the most powerful aspects of the technique is the group reflection on and discussion of the photographs.

The Photovoice Narrative

The storytelling aspect of Photovoice follows the acronym SHOWED:

- What do you See here?
- What's really Happening here?
- How does this relate to Our lives?
- Why does this problem/condition/strength exist?
- How could this image Educate the community, policy makers, etc.?
- What can we Do about it (the problem, condition, or strength)?

By stimulating critical dialogue of the issues raised in the photographs, Photovoice participants generate awareness, not just of problems or concerns, but also of potential solutions and areas of strength with respect to their lives and communities. The images and stories can be shared with an audience in numerous ways including: presentations, exhibits, books, videos, CDs, and on the Internet. Two advances in photography, disposable and digital cameras, offer inexpensive ways of generating images and a wide range of formats for presenting those images. Thus, Photovoice can be carried out in almost any setting with almost any group of people.

Photovoice at the Center for Psychiatric Rehabilitation

In 2005, the Center for Psychiatric Rehabilitation began using Photovoice in a Recovery Education Program class, entitled "Picturing My Health." This class engaged students by using Photovoice to explore health and wellness issues as experienced by adults with psychiatric disabilities. Response was overwhelmingly favorable. Following the success of "Picturing My Health," other Photovoice classes were offered, addressing the topics of recovery, spirituality, work, prejudice and discrimination. The Photovoice classes regarding prejudice and discrimination proved to be a powerful experience for the participants. Each member of the class was able to create photographs exposing the impact of prejudicial attitudes and discriminatory behaviors in his or her life. Each class has 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. Students were able to increase their awareness of how internalized biases served as a barrier to community participation. They also reported feeling stronger and more likely to address prejudicial attitudes and discriminatory behaviors in their worlds.

Recognizing the power of Photovoice in exploring and exposing ignorance, prejudice, and discrimination, the Center for Psychiatric Rehabilitation embarked on a research project which was originally funded by the National Institute on Disability, Independent Living and

Rehabilitation Research (NIDILRR) and the Center for Mental Health Services (CMHS) of the Substance Abuse and Mental Health Services Administration (SAMHSA). The Center developed the Anti-Stigma Photovoice (ASP) program as a manualized peer-run Photovoice psychosocial group intervention meant to foster participants' competence in coping with prejudice and discrimination by focusing on increasing their awareness of prejudice and discrimination, teaching coping strategies, and emphasizing recovery. The effectiveness of the ASP program was tested with a small randomized study conducted with 82 people with the lived experience of mental illness receiving services at our Recovery Center (Russinova et al., 2014; Russinova, Mizock, & Bloch, 2018). Given the promising results from this initial study, the Center received funding from the National Institute on Mental Health (NIMH) for a larger randomized study. This study was conducted at all four clubhouses of the Riverside Community Care, Inc., with a total of 192 participants who were randomly assigned to participate either in the ASP program or a one-hour session reviewing key strategies to address prejudice and discrimination associated with mental illness.

The Anti-Stigma Photovoice Curriculum

This curriculum, consisting of a Workbook and a Leader'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 Leader's Guide provides comprehensive instruction in leading Photovoice workshops. Using the Leader's Guide, an instructor may conduct workshops with little to no other training, though it is ideal if group leaders have group process or teaching skills to bring to the experience. This curriculum will ensure that this Photovoice intervention may be delivered easily at outpatient mental health and rehabilitation settings as well as peer-run programs and centers. To help stimulate interest in this intervention, agencies may opt to display large-scale, full-color posters of actual Photovoice works produced by persons who have taken part in the Combating Prejudice and Discrimination through Photovoice Empowerment program. Detailed information about these posters, including instructions for ordering is available at: <https://cpr.bu.edu/research/>. Also see page 3 of this Leader's Guide for a complete list of companion products to the curriculum.

Each student is given a copy of the workbook for their own reading, taking notes, and completing activities or exercises. The lesson plans for each individual class in this Leader's Guide closely reflect the course material included in the Workbook.

In the Leader's Guide, each lesson plan has a cover sheet with goals for each class and needed materials for that class. The lesson plans are written in a script format for the instructor to follow. The directions to the instructor use "command words," suggesting which type of teaching activities are needed. Listed below are some of the common directions used with an explanation about the type of activity indicated by the command word (Cohen, Danley, & Nemec, 1985).

Command Words

Orient: Gives general directions for what is to happen at the beginning of a class.