

The development of the contents of this publication was supported by funding from the National Institute on Disability and Rehabilitation Research, United States Department of Education, and the Center for Mental Health Services Substance Abuse and Mental Health Services Administration, United States Department of Health and Human Services (NIDRR grant H133B040026). The content does not represent the views or policies of the funding agencies. In addition, you should not assume endorsement by the Federal Government.

Combating Prejudice and Discrimination

through **PhotoVoice Empowerment**

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Philippe Bloch, and Sue McNamara

Leader's Guide



Boston University Center for Psychiatric Rehabilitation

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Published by:

Center for Psychiatric Rehabilitation
College of Health and Rehabilitation Sciences (Sargent College)
Boston University
940 Commonwealth Avenue West
Boston, MA 02215
<http://www.bu.edu/cpr/>

The development of the contents of this publication was supported by funding from the National Institute on Disability and Rehabilitation Research, United States Department of Education, and the Center for Mental Health Services Substance Abuse and Mental Health Services Administration, United States Department of Health and Human Services (NIDRR grant H133Bo40026). The content does not represent the views or policies of the funding agencies. In addition, you should not assume endorsement by the Federal Government.

Cover photo: from “Taking Off the Blinders,” Boston University Center for Psychiatric Rehabilitation PhotoVoice Project, 2005

“This 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 become a drain on me. Education about mental illness (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.”

ISBN: 978-1-878512-46-8

Acknowledgements

We would like to thank all the students who have participated in the PhotoVoice classes in the Recovery Center at Boston University's Center for Psychiatric Rehabilitation. We appreciate their openness, bravery, and hard work in discussing their recovery stories and experiences with prejudice and discrimination. We value their creativity in their PhotoVoice projects that they made. And we appreciate their feedback in the classes as we have developed this curriculum.

We also would like to thank all of the consumer trainers who worked hard co-leading and teaching in the PhotoVoice classes. Their involvement and feedback helped us tremendously to improve and shape this curriculum.

We would like to thank Alexandra (Sasha) Bowers who introduced us to the PhotoVoice research and encouraged the use of PhotoVoice at our Center. We would like to thank Zlatka Russinova who had the vision to use PhotoVoice as a method to teach coping with stigma. Her research of stigma in the mental health field has given richness and depth to the PhotoVoice curriculum.

We would like to thank Bill Anthony, our leader at our Center, who has inspired and supported us to create new curricula to help practitioners and participants in the mental health field. And we would like to thank Linda Getgen for her creative spirit and practical suggestions in developing this curriculum.

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: Boston University, Center for Psychiatric Rehabilitation. <http://www.bu.edu/cpr/products/curricula/groupprocess.html>

A book with personal accounts about recovery and PhotoVoice examples:

McNamara, S. (Ed.). (2009). *Voices of recovery*. Boston: Boston University, Center for Psychiatric Rehabilitation. <http://www.bu.edu/cpr/products/books/titles/voices.html>

A Recovery & Rehabilitation newsletter about PhotoVoice:

Johnson, D., Russinova, Z., & Gagne, C. (2008). Using PhotoVoice to fight the stigma of mental illness. *Recovery & rehabilitation newsletter*, 4(4), 1–4.
<http://www.bu.edu/cpr/resources/newsletter/photovoice/index.html>

A video: “Beyond the Shadow of Stigma”

The DVD is included in this curriculum and the video also is available online at:
<http://www.bu.edu/cpr/research/ongoing/rtc2009/photovoice/index.html>

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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 welcome 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 (Johnson, Russinova, & Gagne, 2008).

Ignorance about mental illnesses, prejudicial attitudes, and discriminatory behaviors experienced by persons with psychiatric disabilities present a major barrier to recovery (New Freedom Commission on Mental Health, 2003). 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; while the subjective experience is associated with avoidance of social interaction and increased depressive symptoms (Dickerson, et al., 2002; Perlick, et al., 2001; Wahl, 1999). According to Zlatka Russinova, Senior Research Associate 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.” 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, et al., 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 (Monahan, 1992; Ryan, et al., 2001; 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 (Corrigan, & Watson, 2002; Link, & Phelan, 2001; Link, et al., 2001; Markowitz, 1998; Perlick, et al., 2001; Ritscher, et al., 2003).

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, others confronting prejudice and discrimination through advocacy and education. This PhotoVoice curriculum is an educational intervention development at our Center 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 the concepts 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 that people or organizations practice that reject or avoid people diagnosed with mental illnesses.

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 (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; rather than health specialists, policy makers, or professionals; to represent and define issues of concern, areas of strength, and targets for change. 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” (www.PhotoVoice.com). PhotoVoice has evolved into a powerful empowerment strategy (Hergenrather, Rhodes, & Clark, 2006; Streng, Rhodes, Ayala, Eng, Arceo, & Phipps, 2004) 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.

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.