

# American Psychological Association

## Recovery to Practice Initiative Curriculum: Reframing Psychology for the Emerging Health Care Environment

August 2014

American Psychological Association & Jansen, M. A. (2014). *Recovery to Practice Initiative Curriculum: Reframing Psychology for the Emerging Health Care Environment*. Washington DC: American Psychological Association.

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### *Instructions for Delivering the Curriculum*

August 2014

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### *Instructions for Delivering the Curriculum*

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## Overview

This curriculum has been designed to train psychologists in the principles associated with helping individuals achieve recovery from serious mental illnesses and in the practices and interventions of psychosocial or psychiatric rehabilitation. The content is broad however and can be used to train other mental health professionals.

The curriculum consists of this Instruction module, fifteen modules on topics of importance for psychologists and other mental health professionals working with persons with serious mental illnesses, and power point presentations that are designed to accompany each of the modules.

Within each of the topical modules, learning objectives, required readings, a sample activity pertaining to the content of the module, and sample evaluation questions are given in addition to the substantive content of the module. Instructors are encouraged to make use of these teaching resources.

Each of the modules in APA's Recovery to Practice Curriculum is based on the most recent scientific literature. In its entirety, the Curriculum presents a comprehensive training program in recovery oriented principles and practices to help people with serious mental health disorders recover and achieve their full functional capability.

The overarching goal of the APA Recovery to Practice Curriculum is to provide doctoral level psychology students with:

- Knowledge of the concept of recovery from severe mental illness and
- Knowledge of rehabilitation assessments and evidence based and emerging practices to assist individuals with severe mental illnesses to achieve their goals and full potential. These are known as psychosocial rehabilitation (PSR) interventions.

## The APA Curriculum modules

### 1. Introduction to Recovery Based Psychological Practice

This module introduces the recovery model applied to behavioral health. Characteristics and fundamental components of recovery are defined.

### 2. Role of Psychologists and Health Care Reform

This module provides a historical overview of the concept of recovery as applied to mental health and describes its evolution. An understanding of the role of psychologists and how health care reform is shaping the future of recovery is explored.

### 3. Assessment

This module discusses clinical assessment methodologies consistent with a recovery framework that are strengths-based and focused on the functional capabilities of the individual.

### 4. Partnership and Engagement

This module examines the importance of engaging people in the service delivery process and presents some of the impediments that keep people from becoming partners in this process. A discussion of how to successfully engage and involve individuals is presented.

### 5. Person-Centered Planning

This module provides an overview of person-centered planning in recovery-oriented care. At its core, person-centered planning is a collaborative and interdisciplinary approach to treatment in which individuals are empowered to find their own path to recovery.

### 6. Health Disparities

This module provides an overview of the causes of the premature death experienced by people with serious mental illnesses and includes a discussion of the intersection of race, ethnicity, gender and culture related to these causes.

### 7. Interventions I: Guiding Principles and Integrated Framework

This module is the first in a series of three intervention modules designed to be used together. Guiding principles that underlie the provision of all psychosocial rehabilitation services (PSR) are discussed, and an integrative framework is presented.

### 8. Interventions II: Evidence Based Practices

This module is the second in a series of three intervention modules designed to be used together. The evidence based practices developed, researched, and found to help people achieve their desired outcomes are presented.

### 9. Interventions III: Promising or Emerging Practices and Supporting Services

This module is the third in the series of intervention modules, and describes services that have shown promise of achieving specified outcomes. Supporting services that are widely acknowledged as essential services for helping people recover from the effects of serious mental illness are also highlighted.

### 10. Issues in Forensic Settings

This module is the first of two forensics modules designed to be used together. This first module highlights the many issues and impediments people with serious mental health disorders face in the justice system.

## 11. Interventions in Forensic Settings

This is the second in the series of two forensics modules designed to be used together. This module presents information about the interventions currently recommended to help people in the system avoid re-incarceration and achieve a stable and satisfying life in the community.

## 12. Community Inclusion

This module presents an overview of the issues that serve to exclude people with mental health disorders from participation in their communities. These include stigma, discrimination, poverty, and vulnerability. The circular and detrimental impact of social isolation and exclusion on an individual's mental health are explored.

## 13. Peer Delivered Services

This module focuses on the role of peers in helping individuals recover and achieve a satisfying and productive life in the community. Peer support as an integral component of the mental health service delivery system is presented.

## 14. Systems Transformation

Transforming a mental health system or an organization to one that is focused on helping people recover requires a fundamental paradigm shift from a system that is provider driven to one that is driven by the individuals who use the system and their families. This module presents key ingredients, challenges, successes and the role of psychologists in systems change.

## 15. Scientific Foundations

This module provides the empirical basis for recovery, and presents the pros and cons of using quantitative versus qualitative methods to study interventions for people with serious mental illnesses. An introduction to mixed methods research, which offers a solution to the problems of using either quantitative or qualitative methods, is presented.

## **Redundancy of Some Important Concepts**

Users of the curriculum may notice that there is some redundancy in some of the modules, i.e., in a few instances, information contained in one module is repeated, or partially repeated in another module. This is because some instructors may choose to emphasize some sections of a module more so than other sections. While the authors of the curriculum do not recommend this, and indeed recommend that every section of all modules be utilized completely, it is recognized that this may not always be possible and relevant information may not be thoroughly covered in a particular module. By repeating certain information where relevant in other modules, it is hoped that all important concepts will be conveyed.

## **A Word about Terminology**

There are several words and phrases that are often used interchangeably. In an effort to simplify use of various terms, the following conventions are used:

The terms psychosocial rehabilitation and psychiatric rehabilitation are used interchangeably in the literature. In this curriculum, the phrase psychosocial rehabilitation is used.

Consumer is (sometimes) used to indicate a person with a serious mental illness, also known as a person with lived experience, a service user, a client, a recipient of services, and primarily in medical circles, a patient or ex-patient.

## **Incorporating Consumers into the Design, Delivery and Evaluation of the Curriculum**

In order to ensure that the perspectives of people with lived experience of serious mental illness are conveyed, it is important that individuals who have experienced serious mental illness are incorporated into the delivery of each of the curriculum modules. It is strongly encouraged that consumers be an integral part of the teaching experience. This can be accomplished through:

Having consumers serve as co-trainers

Inviting consumers to classes to be guest speakers

Showing films or other media that have been produced for teaching the experiences of consumers

In order to ensure adequate preparation and support for those who are asked to take part in the discussion, it may be important to provide advance training and after class debriefing, especially where issues related to trauma have been raised and discussed. See Bassman, 2000 for a full discussion of this issue.

All participants should note the importance of establishing an environment where everyone feels comfortable and safe sharing information. It is important that confidentiality is assured for all information that is shared and any discussions that take place. Information that is shared should never be used to affect an individual's status in the program. No personal information should be shared with anyone who is not part of the class and discussions about personal information that may have been disclosed in the class should not occur outside the classroom.

APA is considering ways to include people with lived experience of serious mental illness, including psychologists, in the delivery of portions of the curriculum via video and other media. When available, these media would be released with future versions of the curriculum.



Learning about recovery from serious mental illness is intended to occur throughout doctoral training. As such, educational experiences are intended to occur in courses, discussions, and other educational fora – wherever opportunities can be made available.

## **Reference**

Bassman, R. (Winter, 2000). Consumers/survivors/ex-patients as change facilitators. *New Directions for Mental Health Services*, 88, 93 – 102.

## **Additional Resources**

American Psychological Association Recovery to Practice Initiative.  
<http://www.apa.org/pi/rtp>

## Acknowledgements

The Recovery to Practice (RTP) Curriculum was developed by the American Psychological Association (APA) and written by Mary A. Jansen, Ph.D.

The authors acknowledge the assistance of the APA RTP Steering Committee (RAC), the APA RTP Committee for Assessment and Training in Recovery (CATR), the APA RTP staff, Andrew Austin-Dailey, M.S., and Urmi Chakrabarti, the APA Task Force on Serious Mental Illness and Severe Emotional Disturbance (TF SMI/SED), the Development Services Group, Inc. (DSG) Program Office, and the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) Recovery to Practice Initiative Program Office.

Members of the RTP RAC include: Peter Ashenden, Arthur C. Evans, Ph.D., Marianne Farkas, Sc.D., Mary A. Jansen, Ph.D., Renee Kopache, M.S., Janis Tondora, Psy.D., and Bruce Zahn, Ed.D.

Members of the RTP CATR include: Ronald Bassman, Ph.D., Arthur Cantos, Ph.D., Jay L. Cohen, Ph.D., Zachary Corcoran, Drew Horn, J. Rock Johnson, J.D., Anne Klee, Ph.D., Roberta L. Nutt, Ph.D., Lawrence S. Schoenfeld, Ph.D., and Scott Spicer, M.P.H.

Members of the APA TF SMI/SED include: Steven Genden, Ph.D., Shirley M. Glynn, Ph.D., Bruce Graunke, Ph.D., Mary A. Jansen, Ph.D., Karen Kangas, Ed.D., Linda K. Knauss, Ph.D., Robert W. Johnson, Ph.D., Susan McCammon, Ph.D., Victor A. Molinari, Ph.D., William A. Newbill, Ph.D., Susan A. Pickett, Ph.D., Sandra G. Resnick, Ph.D., Linda M. Richardson, Ph.D., Jennifer Snyder, Ph.D., and Kiara G. Vogel, M.S.

Funding for the Curriculum was provided by the SAMHSA RTP Initiative through DSG. The views expressed do not necessarily reflect the official policies of SAMHSA, DSG, or the APA. Likewise, mention of trade names, commercial practices, or organizations does not imply endorsement by the U.S. Government, DSG, or the APA.

## Citing the Curriculum

Citation for this Module:

American Psychological Association & Jansen, M. A. (2014). Instructions for Delivering the Curriculum. *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

Citation for the full Curriculum:

American Psychological Association & Jansen, M. A. (2014). *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

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## Recovery to Practice Initiative Curriculum: Reframing Psychology for the Emerging Health Care Environment

### *1. Introduction to Recovery Based Psychological Practice*

August 2014

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## Overview

In this module, we will discuss the concept of recovery for people with severe mental illness and learn about the principles on which the recovery model is based.

## Learning Objectives

At the end of this module you will be able to:

- Describe four points related to the concept of recovery from serious mental illness
- Discuss two points related to the historical context from which the recovery movement arose and describe the evolution of the movement
- State three reasons for mental health practitioners' reluctance to accept the validity of recovery from serious mental illness
- List and describe the ten guiding principles elucidated by SAMHSA in 2006
- Identify at least two challenges faced by people with serious mental illness as they work to recover
- Discuss at least three actions mental health practitioners need to take to help overcome these challenges

## Resources

- Lecture Notes
- Required Readings
- Lecture Notes Citations
- Sample Learning Activity
- Sample Evaluation Questions
- Additional Resources

## Required Readings

Anthony, W. A. (2004). The principle of personhood: The field's transcendent principle. *Psychiatric Rehabilitation Journal*, 27, 205.

Deegan, P. (2006). *Recovery as a Self-Directed Process of Healing and Transformation*. Available from: <https://www.patdeegan.com/store/products/recovery-self-directed-process-healing-and-transformation>.

Farkas, M. (2007). The vision of recovery today: What it is and what it means for services. *World Psychiatry*, 6, 68-74.

Mead, S. & Copeland, M. E. (2000). What recovery means to us: Consumers' perspectives. *Community Mental Health Journal*, 36, 3, 315-328.

Mueser, K. T. (2012). Evidence-based practices and recovery-oriented services: Is there a relationship? Should there be one? *Psychiatric Rehabilitation Journal*, 35, 4, 287-288.

O'Connell, M., Tondora, J., Croog, G., Evans, A. & Davidson, L. (2005). From rhetoric to routine: Assessing perceptions of recovery-oriented practices in a state mental health and addictions system. *Psychiatric Rehabilitation Journal*, 28, 4, 378-386.

Walsh, D. (1996). A journey toward recovery: From the inside out. *Psychiatric Rehabilitation Journal*, 20, 2, 85-89.

## Activities

Complete the following activities:

- Read the lecture notes
- Read the required readings
- Engage in a learning activity related to this module
- Evaluate students' understanding of this module.



## Lecture Notes

People with lived experience of serious mental illness are strongly encouraged to be part of the delivery of the curriculum including being active participants in the delivery of the lecture. Refer to the curriculum Instruction module for additional information.

### Introduction

The concept of recovery from mental illness, especially severe mental illnesses such as schizophrenia, schizo-affective disorders, bi-polar disorder, and other illnesses severe enough to include psychotic episodes in their symptomatology, was foreign to most mental health practitioners until the mid 1970s.

Until this time, psychologists and other practitioners generally believed that individuals with serious mental illness would be chronically ill and would not be able to function in society.

As a result, this pessimism was communicated to people with the disorders and they too felt hopeless, useless, and generally considered themselves doomed to a life of institutionalization or at best, repeated hospitalizations.

However, this began to change in the mid-1970s when long term studies from several countries began to show that people from all over the world who had these disorders and who had been hospitalized for long periods of time, were able to live in the community and lead satisfying lives. At about the same time, people with the illnesses also began to notice that, given the opportunity and appropriate supports where needed, they could live successfully in the community and did not need continuous hospitalization. Many individuals began to work in regular jobs, and many others were able to live without assistance in homes of their choice.

These two factors - long term studies showing that people can and do make substantial progress on their recovery journey, and individuals themselves realizing that there is the real possibility of recovering and living successfully in the community - led to the development of the recovery movement in several countries around the world.

### Evolution of the Recovery Movement

The recovery movement evolved from the work of disability rights advocates who argued for inclusion of individuals and their families in the planning and service delivery process and argued that people with disabilities should be considered full members of their community and the larger society. These efforts also paralleled those of the civil rights movement that was working for inclusion and full citizenship for people from all races and cultures. These efforts culminated in the push for better research and for trauma informed service delivery systems that are respectful and that include consumers as decision makers, ultimately leading to what is known today as the recovery movement.

The concept of recovery has not been an easy sell for most mental health practitioners, including psychologists. Until about the mid 1990s, the movement was principally advanced by people with the illnesses themselves.

The reasons for practitioners' reluctance are easy to discern. As disparaging as it may seem, most mental health practitioners did not want to lose their status as "the doctor" or "the professional" who knew what was best for the person being served. Additionally, mental health practitioners, even to this day, are often not trained to accept the concept of recovery or to provide the interventions that are most helpful to people with serious mental illnesses, i.e., those interventions that can help people live successful lives in the community. On the contrary, most practitioners, including psychologists, are trained to see serious mental illnesses as chronic deteriorating illnesses and to provide traditional mental health treatment, i.e., medications, psychotherapy, etc. While these may be of assistance, they are not sufficient to help those with serious mental illness learn to live successfully in the community. In fact, despite the long held and pervasive beliefs about the deteriorating course of serious mental illnesses, several meta analyses and summaries of well conducted studies have been published and all continue to document that individuals with serious mental illnesses can, and do recover from the effects of their illness (Warner, 2010), and indeed that most have the potential to achieve long-term remission and functional recovery (Zipursky, Reilly & Murray, 2012).

At this point, you might be asking yourself why people with serious mental illness would need help to learn how to live in the community. After all, everyone grows up, finishes school, and seemingly effortlessly moves out into the world to live on his or her own. However, the majority of people with serious mental illness experience their first symptoms in early adolescence and their first psychotic episode between the ages of 16 and 26. Prior to their first episode of psychosis, they are often in considerable distress as they may hear and see strange things, become socially isolated, have difficulty concentrating, and may not be able to learn age appropriate concepts and behaviors. All of this comes at a crucial developmental stage when most young people are completing formal education and acquiring the informal knowledge needed to communicate and interact with peers, educators, family members, friends, co-workers and work supervisors. For the majority of young people who develop serious mental illness, these developmental learnings are not acquired. And even where good early psychosis intervention programs are in place, these young people may spend considerable time in treatment before their illness is stable enough to allow them to resume their education or attain vocational pursuits. In order to help individuals with serious mental illnesses overcome the developmental deficits that frequently occur, mental health practitioners must be trained to offer the specialized interventions that constitute psychosocial rehabilitation.

A major turning point and step forward occurred in 2003, when the U.S. President's New Freedom Commission on Mental Health published the Final Report of their work, entitled "Achieving the Promise: Transforming Mental Health Care in America" (President's New

Freedom Commission Report, 2003). The Report has had an enormous impact on mental health systems of care throughout the United States because it gave legitimacy and a “push” to mental health systems that were on the cusp of embracing a more recovery oriented approach to mental health treatment. The Report contains many recommendations, all geared toward encouraging a transformed system of care to one which promotes recovery for people with serious mental illness. A hallmark of the Report, and perhaps it’s essence, is the recommendation that consumers and family members are to be full partners in the decision making process about which services are provided and about the professionals that will provide those services. Since publication of the President’s New Freedom Commission Report, many changes have occurred throughout the country and many systems have moved closer to the ideals espoused in the Report. This is not true everywhere however, and there remains much work to be done, especially among established practitioners and administrators, many of whom are still resistant to change.

By the end of the first decade of the twenty first century (2010), the concept of recovery from serious mental illness had become fairly well known and was of interest to many mental health practitioners including psychologists. However, knowing how to implement the concept in practice and having the ability to appropriately use the proper interventions are skills that were then, and continue to be foreign to most practitioners (Mueser, 2012).

In an effort to encourage mental health practitioners to learn about the possibilities that exist for recovery from serious mental illness and learn how to provide appropriate rehabilitative interventions, the U.S. federal agency with responsibility for mental health services, the Substance Abuse and Mental Health Services Administration (SAMHSA), provided funding to the major mental health professional associations to develop a curriculum specifically focused on recovery oriented practices for their profession. In recognition of the need to train psychologists to appropriately work with people with serious mental illnesses, the American Psychological Association undertook the development of its curriculum using the funding provided by SAMHSA. This module is the introductory chapter for that curriculum. The goals of the APA curriculum are to train psychologists to:

- End discrimination and pessimism in prognosis
- Train psychologists to adequately and appropriately provide services that have been shown to be effective in helping people recover their full potential
- Make self-determination and choice central
- Ensure community and social inclusion
- Adhere to the fundamentals of consumer and family-driven interventions using ecological, multicultural, and trauma informed perspectives
- Use recovery-oriented outcome measures.

## Guiding Principles of Recovery from Serious Mental Illness

Recovery is based on the “novel” idea that individuals with serious mental illness can and do recover and live productive and meaningful lives in the community – just like anyone with an illness that may flare up from time to time. A recovery oriented framework is one which is driven by the person with the illness and one which operates from a belief, shared by the mental health team, and actively communicated to the person, that recovery can occur and should be expected.

The process of recovery is aided by the provision of interventions to help people with serious mental illness recover their full potential. These interventions are known as psychosocial rehabilitation (PSR) interventions. The primary focus of PSR services is on improving the capabilities and competencies of persons with serious mental health disorders, similar to the focus of rehabilitation interventions for persons with physical impairments or disorders.

Many professionals and consumers alike have written about the philosophy and process of recovery from serious mental illness. Some notable statements that are often quoted are:

- Recovery is what people with illnesses and disabilities do (Anthony, 1993).
- Treatment, case management, support and rehabilitation are the things that practitioners do to facilitate recovery (Anthony, 1993).
- Recovery is a journey of healing and transformation enabling a person with a mental health problem to live a meaningful life in a community of his or her choice while striving to achieve his or her full potential (Substance Abuse and Mental Health Services Administration, 2006).
- A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential (Substance Abuse and Mental Health Services Administration, 2012).
- Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness (Anthony, 1993).

Despite the severity of the conditions that many people have, people with serious mental illnesses want the same things from life that everyone else wants: meaningful relationships, a safe place to live, satisfying activities, adequate income, job satisfaction, and an enjoyable social life. Yet, for many people with serious mental illness, these everyday pursuits are not easily within reach. This remains true today, despite the years of research that show that recovery and a satisfying life are possible. There are many reasons for this including stigma, social exclusion, and failure of treatment systems to provide needed services, to name but a few. These and other issues are discussed in subsequent modules of this curriculum.

Through its Recovery Support Strategic Initiative, SAMHSA delineated four major dimensions that support a life in recovery (Substance Abuse and Mental Health Services Administration, 2012):

- Health: Overcoming or managing one's disease(s) as well as living in a physically and emotionally healthy way;
- Home: A stable and safe place to live;
- Purpose: Meaningful daily activities, such as a job, school, volunteerism, family caretaking, or creative endeavors, and the independence, income, and resources to participate in society;
- Community: Relationships and social networks that provide support, friendship, love, and hope.

There are several principles upon which the concept of recovery is based. These were elucidated at the 2006 SAMHSA National Consensus Conference and updated in 2012 and include:

## Ten Fundamental Components of Mental Health Recovery

<p><b>Self-Direction: Consumers lead, control, exercise choice over, and determine their own path of recovery by optimizing autonomy, independence, and control of resources to achieve a self-determined life.</b></p> <p><b>Individualized and Person-Centered: There are multiple pathways to recovery based on an individual’s unique strengths and resiliencies as well as his or her needs, preferences, experiences (including past trauma), and cultural background in all of its diverse representations.</b></p> <p><b>Empowerment: Consumers have the authority to choose from a range of options and to participate in all decisions—including the allocation of resources—that will affect their lives, and are educated and supported in so doing.</b></p> <p><b>Holistic: Recovery encompasses an individual’s whole life, including mind, body, spirit, and community.</b></p> <p><b>Non-Linear: Recovery is not a step-by-step process but one based on continual growth, occasional setbacks, and learning from experience.</b></p>	<p><b>Strengths-Based: Recovery focuses on valuing and building on the multiple capacities, resiliencies, talents, coping abilities, and inherent worth of individuals.</b></p> <p><b>Peer Support: Mutual support—including the sharing of experiential knowledge and skills and social learning—plays an invaluable role in recovery.</b></p> <p><b>Respect: Community, systems, and societal acceptance and appreciation of consumers—including protecting their rights and eliminating discrimination and stigma—are crucial in achieving recovery.</b></p> <p><b>Responsibility: Consumers have a personal responsibility for their own self-care and journeys of recovery.</b></p> <p><b>Hope: Recovery provides the essential and motivating message of a better future—that people can and do overcome the barriers and obstacles that confront them.</b></p>
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A growing body of research continues to support the principles defined in the table above (Warner, 2010). These principles form the underlying basis for helping people recover from serious mental illness and achieve satisfying lives in the community. They are crucial to success.

## Challenges

For someone with a serious mental illness, recovery involves many challenges. Some of these challenges stem from the illness itself, some come from society's beliefs about people with serious mental illnesses, and some of the challenges come from the mental health system. Public stigma and discrimination can cause individuals to internalize society's stigma, disavow their potential, and isolate themselves. These challenges are made worse for individuals from already marginalized groups such as those with physical disabilities and those from racial or ethnic minorities who can be further isolated due to lack of access to services, including culturally appropriate services.

These challenges often become circular and self fulfilling because with each recurrence or episode of illness, the person can lose hope that the illness can be managed, family, friends, and acquaintances can further ostracize and stigmatize the individual, and the treatment system can continue to fail and dehumanize the person. People with serious mental illness, their families, and mental health practitioners often have low expectations of what is achievable and frequently lack knowledge about what symptoms or behaviors are due to illness and what are due to the person's and society's reaction to that illness. This often leads to a downward spiral for the affected individual and the effect can be traumatizing. Much of this trauma is iatrogenic and can be avoided if the treatment system has a recovery orientation.

The majority of people with serious mental illness have experienced trauma, much of it severe. A considerable amount of this trauma has likely occurred at the hand of the treatment system itself, which often treats people with dis-respect and in dehumanizing ways.

Trauma that comes from the treatment system may be additive to trauma from societal discrimination that someone with serious mental illness has experienced prior to entering into treatment. Many individuals with serious mental illness have experienced severe sexual, physical, and emotional abuse at the hands of family members who either perpetrated the abuse or ignored it, thereby allowing it to continue. Despite the impact of this abuse on the development of serious mental illness, it is often not acknowledged due to fear of reprisal, fear of being blamed, or because of the stigma that is frequently attached to victims of abuse, especially sexual abuse.

Trauma at the hands of family members or others should always be considered a potential factor in the etiology of serious mental illness and is an important consideration when people with serious mental illness are asked if they wish their family members to be active participants in their treatment decisions. For the reasons mentioned above, this can be quite challenging for the individual, especially if abuse occurred. It is also important to keep in mind that the makeup of the family constellation may have changed. Individuals who were part of the family in years past may no longer be part of the individual's familial sphere and current family members may be highly supportive. Social connectedness is

important for all of us and for many with serious mental illnesses, family is the prime connection; many times relationships can be positive and nurturing. These are complex and sensitive issues that should be discussed with the individual, keeping in mind that trauma is often hidden and is always very difficult to acknowledge and discuss. Mental health practitioners must be highly sensitive and recognize the person's fears related to stigma, the possibility of being blamed for trauma and abuse. Ultimately, the individual's right to privacy must be respected.

As noted above, practitioners more often than not are unaware of the PSR interventions that have been shown to be effective in helping people with serious mental illness re-gain functional capacity to live satisfying lives in the community. Many of these interventions have been rigorously tested and have been shown to be effective, earning the designation of evidence based practices (EBPs). Unfortunately, far too few providers understand how to provide them and far too mental health systems have allocated the resources to implement them. This lack of will to provide these interventions even when knowledge of their effectiveness is present is a major stumbling block in efforts to help people with serious mental illnesses achieve their recovery goals. In the current economic climates faced by governments around the world, there can be a reluctance to apply the resources needed to provide interventions to bring about optimal recovery – this is frequently the case despite the potential economic gain from reduced hospitalizations and potential revenues generated by consumers who have regained the ability to purchase goods and pay taxes. These potential benefits are most often overlooked however as service delivery systems make choices about the services to be offered.

In a nutshell, the challenges that people with serious mental illnesses have include:

- Dealing with diagnoses that are stigmatizing and imply a sense of permanent disability and impairment
- Challenging and overcoming the stigma that they have incorporated into their very being
- Recovering from the iatrogenic effects of treatment settings
- Recovering from the negative effects of unemployment
- Recovering from the effects of crushed dreams
- Fighting for the right to receive effective interventions that will enable them to live satisfying and productive lives.

In order to help people with serious mental illness overcome these challenges, we need to:

- Ensure that mental health practitioners are appropriately and adequately trained
- Change the attitude of existing staff and those being trained in traditional professional training programs in order to eliminate the stigma that many professionals have even today



- Ensure that psychotherapy with a skilled therapist is available to everyone in order to assist with understanding the illness and what it means to each individual person
- Implement education programs and opportunities for contact with persons with serious mental illnesses to overcome stigma and discrimination
- Change the service delivery system from one which delivers only medication and psychotherapy to one which focuses on provision of rehabilitation services and the potential of each person to recover to the greatest extent possible.

## Summary

Recognition that people with serious mental illnesses can recover and lead satisfying lives has been building since the mid 1970s when several international studies showed that this was not only possible, but was in fact occurring. At around the same time, consumers themselves began to be empowered to assert their belief that recovery is possible and began to seek greater participation in decisions about their treatment.

Since that time, the empirical literature and first person accounts have continued to document the possibilities for recovery and to elucidate the conditions under which recovery is facilitated.

Despite publications, reports from government commissions, and government funding designed to facilitate change, professionals have been slow to fully embrace the recovery model. For most professionals, the concept remains foreign and is more often than not, viewed with skepticism.

In an effort to change this, the Substance Abuse and Mental Health Services Administration (SAMHSA) provided funding to the major mental health professional organizations to develop and implement a training curriculum for their profession that is designed to enable current and future practitioners to be knowledgeable and competent to provide services that will facilitate recovery.

Many challenges remain. These range from individual lack of knowledge and resistance to systems level issues such as inertia, lack of funding, and resistance – systems are ultimately led by individuals! Frustration on the part of consumers and practitioners alike is another challenge: recovery from serious mental illness is often a complex, time-consuming process – just as it is with any serious illness. There is no quick fix!

In order to assist those with serious mental illness to recover, psychologists must recognize and embrace the philosophy of recovery and transmit that philosophy to consumers themselves, their families, others in society, and the mental health treatment systems in which they work. Psychologists' focus on positivism, respect, and individual strengths can be the starting point for additional training in how to help people with serious mental illnesses recover, achieve their life goals and live satisfying and productive lives.

In order to assist people with serious mental illness to recover, psychologists also need to be fully trained in the PSR interventions that have been shown to be effective in helping people achieve a satisfying and productive life in the community of their choice.

The table below depicts the differences in a traditional approach to a person with serious mental illness versus a recovery oriented response to situations that might be encountered. The scenarios presented are instructive as the traditional versus recovery oriented approaches result in vastly different ways of working with people with these conditions.

## Moving from a Deficit-Based to a Strengths-Based Approach to Care

The following are examples of how language, thinking, and practice shift in the evolution of a recovery-oriented system of care

Presenting Situation	Deficit-based Perspective		Recovery-oriented, Asset-based Perspective	
	Perceived Deficit	Intervention	Perceived Asset	Intervention
<b>Person re-experiences symptoms</b>	Decompensation, exacerbation, or relapse	Involuntary hospitalization; warning or moralizing about “high risk” behavior (e.g., substance use or “non-compliance”)	Re-experiencing symptoms as a normal part of the recovery journey; an opportunity to develop, implement, and/or apply coping skills and to draw meaning from managing an adverse event	Express empathy and help person avoid sense of demoralization; highlight how long it may have been since symptoms had reappeared; provide feedback about the length of time it takes to achieve sustained change; offer advice on strategies to cope; reinforce sense of self-efficacy
<b>Person demonstrates potential for self-harm</b>	Increased risk of suicide	Potentially intrusive efforts to “prevent suicide”	Indicators of potential for self-harm are important signals to respond differently. The person is likely to have a weakened sense of efficacy and feel demoralized, and thus may require additional support. On the other hand, the person has already survived tragic circumstances and extremely difficult ordeals, and should be praised for his or her prior resilience and perseverance	Rather than reducing risk, the focus is on promoting safety. Supportive, ongoing efforts are oriented to “promote life,” e.g., enabling people to write their own safety/ prevention plans and advance directives. Express empathy; reinforce efficacy and autonomy; enhance desire to live by eliciting positive reasons and motivations, with the person, not the provider, being the source of this information
<b>Person takes medication irregularly</b>	Person lacks insight regarding his or her need for meds; is in denial of illness; is non-compliant with treatment; and needs monitoring to take meds as prescribed	Medication may be administered, or at least monitored, by staff; staff may use cigarettes, money, or access to resources as incentives to take meds; person is told to take the meds or else he or she will be at risk of relapse or decompensation, and therefore may need to be hospitalized	Prefers alternative coping strategies (e.g., exercise, structures time, spends time with family) to reduce reliance on medication; has a crisis plan for when meds should be used. Alternatively, behavior may reflect ambivalence regarding medication use which is understandable and normal, as approximately half of people with any chronic health condition (e.g., diabetes, asthma) will not take their medication as prescribed	Individual is educated about the risks and benefits of medication; offered options based on symptom profile and side effects; and is encouraged to consider using meds as one tool in the recovery process. In style and tone, individual autonomy is respected and decisions are ultimately the person and his or her loved one’s to make. Explore person’s own perspective on symptoms, illness, and medication and invite him or her to consider other perspectives. Person is resource for important ideas and insights into the problem and is invited to take an active role in problem solving process

Presenting Situation	Deficit-based Perspective		Recovery-oriented, Asset-based Perspective	
	Perceived Deficit	Intervention	Perceived Asset	Intervention
<b>Person makes poor decisions</b>	Person's judgment is impaired by illness or addiction; is non-compliant with directives of staff; is unable to learn from experience	Potentially invasive and controlling efforts to "minimize risk" and to protect the person from failure, rejection, or the other negative consequences of his or her decisions	Person has the right and capacity for self-direction (i.e., Deegan's "dignity of risk" and the "right to fail"), and is capable of learning from his or her own mistakes. Decisions and taking risks are viewed as essential to the recovery process, as is making mistakes and experiencing disappointments and set backs. People are not abandoned to the negative consequences of their own actions, however, as staff stand ready to assist the person in picking up the pieces and trying again	Discuss with the person the pros, cons, and potential consequences of taking risks in the attempt to maximize his or her opportunities for further growth and development. This dialogue respects the fact that all people exercise poor judgment at times, and that making mistakes is a normal part of the process of pursuing a gratifying and meaningful life. Positive risk taking and working through adversity are valued as means of learning and development. Identify discrepancies between person's goals and decisions. Avoid arguing or coercion, as decisions made for others against their will potentially increase their learned helplessness and dependence on professionals
<b>Person stays inside most of the day</b>	Person is withdrawing and becoming isolative; probably a sign of the illness; can only tolerate low social demands and needs help to socialize	Present the benefits of spending time outside of the house; offer the person additional services to get the person out of the house to a clubhouse, drop-in center, day program, etc	Person prefers to stay at home; is very computer savvy; and has developed skills in designing web pages; frequently trades e-mails with a good network of NET friends; plays postal chess or belongs to collectors clubs; is a movie buff or enjoys religious programs on television. Person's reasons for staying home are seen as valid	Explore benefits and drawbacks of staying home, person's motivation to change, and his or her degree of confidence. If staying home is discordant with the person's goals, begin to motivate for change by developing discrepancies. If leaving the house is important but the person lacks confidence, support self-efficacy, provide empathy, offer information/advice, respond to confidence talk, explore hypothetical change, and offer to accompany him or her to initial activities
<b>Person denies that he or she has a mental illness and/or addiction</b>	Person is unable to accept illness or lacks insight	Educate and help the person accept diagnoses of mental illness and/or addiction; facilitate grieving loss of previous self	Acceptance of a diagnostic label is not necessary and is not always helpful. Reluctance to acknowledge stigmatizing designations is normal. It is more useful to explore the person's understanding of his or her predicament and recognize and explore areas for potential growth	In addition to exploring person's own understanding of his or her predicament, explore symptoms and ways of reducing, coping with, or eliminating distress while eliciting ways to live a more productive, satisfying life

Presenting Situation	Deficit-based Perspective		Recovery-oriented, Asset-based Perspective	
	Perceived Deficit	Intervention	Perceived Asset	Intervention
<b>Person sleeps during the day</b>	Person's sleep cycle is reversed, probably due to illness; needs help to readjust sleep pattern, to get out during the day and sleep at night	Educate the person about the importance of sleep hygiene and the sleep cycle; offer advice, encouragement, and interventions to reverse sleep cycle	Person likes watching late-night TV; is used to sleeping during the day because he or she has always worked the night shift; has friends who work the night shift so prefers to stay awake so she or he can meet them after their shift for breakfast. Person's reasons for sleeping through the day are viewed as valid	Explore benefits and drawbacks of sleeping through the day, the person's motivation to change, the importance of the issue and his or her degree of confidence. If sleeping through the day is discordant with the person's goals, begin to motivate change by developing discrepancy, as above
<b>Person will not engage in treatment</b>	Person is non-compliant, lacks insight, or is in denial	Subtle or overt coercion to make person take his or her medications, attend 12-step or other groups, and participate in other treatments; alternatively, discharge person from care for non-compliance	Consider range of possible reasons why person may not be finding available treatments useful or worthy of his or her time. It is possible that he or she has ambivalence about treatment, has not found treatment useful in the past, did not find treatment responsive to his or her needs, goals, or cultural values and preferences. Also consider factors out-side of treatment, like transportation, child care, etc. Finally, appreciate the person's assertiveness about his or her preferences and choices of alternative coping and survival strategies	Compliance, and even positive behaviors that result from compliance, do not equate, or lead directly, to recovery. Attempts are made to understand and support differences in opinion so long as they cause no critical harm to the person or others. Providers value the "spirit of noncompliance" and see it as sign of the person's lingering energy and vitality. In other words, he or she has not yet given up. Demonstrate the ways in which treatment could be useful to the person in achieving his or her own goals, beginning with addressing basic needs or person's expressed needs and desires; earn trust
<b>Person reports hearing voices</b>	Person needs to take medication to reduce voices; if person takes meds, he or she needs to identify and avoid sources of stress that exacerbate symptoms	Schedule appointment with nurse or psychiatrist for med evaluation; make sure person is taking meds as prescribed; help person identify and avoid stressors	Person says voices have always been there and views them as a source of company, and is not afraid of them; looks to voices for guidance. Alternatively, voices are critical and disruptive, but person has been able to reduce their impact by listening to walkman, giving them stern orders to leave him or her alone, or confines them to certain parts of the day then they pose least interference. Recognize that many people hear voices that are not distressing	Explore with person the content, tone, and function of his or her voices. If the voices are disruptive or distressing, educate person about possible strategies for reducing or containing voices, including but not limited to medication. Ask person what has helped him or her to manage voices in the past. Identify the events or factors that make the voices worse and those that seem to make the voices better or less distressing. Plan with the person to maximize the time he or she is able to manage or contain the voices

Source: Tondora & Davidson, 2006

## Sample Learning Activity

Class discussion and consensus activities should be completed with one or more people with lived experience as participants. There are two parts to this exercise.

The first part of the activity is a short video which should be played for the entire class. The video can be accessed via the link:

[https://onedrive.live.com/edir?resid=7086A6423672C497!162&authkey=!AL\\_8-sI4cV1btK4&ithint=video%2c.mp4](https://onedrive.live.com/edir?resid=7086A6423672C497!162&authkey=!AL_8-sI4cV1btK4&ithint=video%2c.mp4)

The second part of the activity should follow the video and involves class discussion using the following questions:

1. What stood out for you in the clip and why?
2. How did you feel emotionally mid-way through the clip? How did you feel at the end?
3. What did you learn?
4. What if YOU were defined largely by ONE attribute/part of yourself – a part you really struggle with – maybe an illness, maybe a difficult experience in your life. What if that was what others focused on most all the time? What would that be like?
5. How do you get to know people with serious mental illnesses as whole people beyond their diagnoses?

## Sample Evaluation Questions

<u>Question</u>	<u>True</u>	<u>False</u>
1. Recovery is the reduction or remission of symptoms of mental illness		X
2. The pursuit of a satisfying life in the community and valued roles is important for recovery	X	
3. Recovery from serious mental illness is supported by consumer experience and research evidence	X	
4. The goal of recovering is to become normal		X
5. Providers and family members are the most qualified to determine a person's care		X

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## Additional Resources

American Psychological Association Recovery to Practice Initiative.

<http://www.apa.org/pi/rtp>

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## Citing the Curriculum

Citation for this Module:

American Psychological Association & Jansen, M. A. (2014). Introduction to Recovery Based Psychological Practice. *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

Citation for the full Curriculum:

American Psychological Association & Jansen, M. A. (2014). *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

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# American Psychological Association

## **Recovery to Practice Initiative Curriculum: Reframing Psychology for the Emerging Health Care Environment**

### ***2. The Recovery Movement: Role of Psychologists and Health Care Reform***

August 2014

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## Overview

In this module of the course we will discuss the history of the recovery movement and consider the roles of psychologists and the potential impact of U.S. health care reform.

## Learning Objectives

At the end of this module you will be able to:

- Discuss at least two contributions made by psychologists to the evolution of the recovery movement in mental health
- Identify four roles of psychologists and describe the difference within each between traditional functions and functions of psychologists in a recovery oriented framework or system
- List at least two benefits that are expected to accrue to people with serious mental illness as a result of the Patient Protection and Affordable Care Act of 2010
- List and describe at least two opportunities for psychologists as a result of the Patient Protection and Affordable Care Act of 2010

## Resources

- Lecture Notes
- Required Readings
- Lecture Notes Citations
- Sample Learning Activity
- Sample Evaluation Questions
- Additional Resources

## Required Readings

American Psychological Association. (March 31, 2010). *Health Care Reform Legislation: Key Provisions of Interest to Psychology*. Washington, DC: American Psychological Association Practice Organization.

Anthony, W. & Ashcraft, L. (2010). The Recovery Movement. In B. Lubotsky Levin, J. Petrila & K. Hennessy (Eds.). *Mental Health Services: A Public Health Perspective (3rd edition)*. New York: Oxford University Press.

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Warner, R. (2010). Does the scientific evidence support the recovery model? *The Psychiatrist Online*, 34, 3-5.

## Activities

Complete the following activities:

- Read the lecture notes
- Read the required readings
- Engage in a learning activity related to this module
- Evaluate students' understanding of this module.

## Lecture Notes

People with lived experience of serious mental illness are strongly encouraged to be part of the delivery of the curriculum including being active participants in the delivery of the lecture. Refer to the curriculum Instruction module for additional information.

### Introduction

Psychologists have been at the forefront of the recovery movement since its beginnings in the mid 1970s when psychologist Dr. Bill Anthony started the Boston University Center for Psychiatric Rehabilitation and others such as Dr. Larry Davidson began writing about the concept of recovery from serious mental illness. At about the same time, individuals with serious mental illnesses began writing about their experiences and documenting their personal histories of recovery. Some of these individuals are also psychologists who have published extensively on the topic and include Dr. Ron Bassman, Dr. Patricia Deegan, Dr. Fred Frese, and Dr. Kay Redfield Jamison, to name but a few. Following from this, psychologists (and other mental health practitioners) initiated research on the outcomes associated with various interventions. Their resulting publications showed that indeed, people with serious mental illnesses were recovering and living satisfying lives.

Concurrently, researchers in several countries began publishing long term outcome data showing that people with serious mental illnesses all over the world had similar recovery rates. Then, in the mid 1980s, psychologist Dr. Courtenay Harding published a study of people in Vermont with serious mental illness, which documented their recovery, and successes in the community. Finally, in the mid 1990s, Harding published a landmark compendium of studies which pulled together the evidence from several countries, all of which documented similar rates of recovery from serious mental illnesses (Harding & Zahniser, 1994). A synthesis of these and more recent studies is provided in the table below:

## Schizophrenia Recovery Research

Study	Sample Size	Average Length Years	Percent Recovered or Significantly Improved
Bleuler 1972 to 1978 Switzerland	208	23	53-68
Hinterhuber 1973 Austria	157	30 apprx	75
Huber et al 1975 Germany	512	22	57
Chiompi & Muller 1976 Switzerland	289	37	53
Kreditor 1977 Lithuania	115	20+	84
Tsuang et al 1977 USA	200	35	46
Marinow 1986 Bulgaria	280	20	75
Harding et al 1987b 1987c USA	269	32	62, 68
Ogawa et al 1987 Japan	140	22.5	56
Desisto et al 1995a 1995b USA	269	35	49
Marneros et al 1992	148	25	58
Harrison et al 2001 worldwide	1005	15 and 25	43 - 61
Hopper et al Sz Only Incidence	502	13 to 17	67
Hopper et al Sz Only Prevalence	142	26	63

Additionally, despite long held beliefs that serious mental illnesses are chronic deteriorating illnesses, several meta analyses and summaries of recently conducted studies have appeared and all continue to document that individuals with serious mental illnesses can, and do recover from the effects of their illness (Warner, 2010) and indeed most have the potential to achieve long-term remission and functional recovery (Zipursky, Reilly & Murray, 2012).

Since then, and continuing to the present, psychologists, together with consumers, have led efforts to conduct research on recovery outcomes, and have developed and tested instruments designed to assess functional skills. Psychologists have also developed and tested psychosocial rehabilitation (PSR) interventions to assist with the recovery process, conducted clinical trials to identify evidence based PSR interventions, and psychologists and consumers have worked with state and federal government agencies to promote practices that are designed to facilitate the recovery process for people with serious mental illnesses.

### Psychologists' Roles in a Recovery Oriented System versus a Traditional Mental Health System: Similarities and Differences

Psychologists generally work within certain roles such as clinician, researcher, manager/administrator, teacher, or policy maker, to name the most common. These roles were recently described in detail for psychologists working in medical centers (Robiner, Dixon, Miner & Hong, 2014) and are similar to psychologists' roles in other settings. Working from a recovery framework however, means approaching these traditional roles from a different perspective. No matter what role psychologists undertake, successful



transformation of the mental health system to a recovery orientation requires a commitment to helping people recover to the greatest extent possible, and doing so on their terms, not our terms or those of other professionals or the service delivery system. Some examples of roles and the opportunities offered by each one are discussed below.

### **Psychologists as Clinicians**

Although psychologists are trained to establish a strong therapeutic alliance, psychologists working in a recovery oriented framework must approach people very differently. In a traditional therapeutic setting, psychologists often become the leader, the doctor, or the professional who is seen as having most of the answers and who knows what is best for the client. In a recovery oriented setting, psychologists must be partners with the person they are working with and must demonstrate this partnership by conveying true respect for the person and for his or her wishes and goals.

Another difference within the clinical setting has to do with assessments that psychologists conduct. Most traditional psychological assessments are designed to determine symptomatology, mental state, or diagnosis. Recovery oriented psychologists work with people to determine their strengths, functional skill capabilities and deficits, assess resources needed to increase functional skills and overcome deficits, and assist with goal setting based on skills and resources needed and available to achieve those goals.

A third difference that exists within the clinical setting has to do with psychotherapy and PSR interventions. While some persons with serious mental illness may desire traditional psychotherapeutic approaches, others may not, instead choosing to focus on interventions that can help with practical problems such as overcoming cognitive deficits, developing the ability to deal with symptoms better by challenging unwanted thoughts, learning appropriate work behaviors, learning how to manage medications and symptom flare-ups, etc. These more practical interventions are some of those that make up the armamentarium of PSR that psychologists helped develop and test. These are the interventions that people with serious mental illness often want because of their direct link to living successfully in the community and psychologists need to be adequately trained to provide them.

### **Psychologists as Researchers**

The research skills that psychologists learn in traditional training programs are the same ones that are used in recovery oriented research. What may differ are the topics and hypotheses generated as these may (although not always) be more person centered and or qualitative than traditional psychological research. A significant difference is the involvement of people with serious mental illness in the design and implementation of recovery oriented research studies.

For example, psychologists studying the recovery process may want to learn about the most efficacious means to assist people determine the goals they have for themselves. Or a recovery oriented psychologist researcher may want to help people understand their own

internal processes that influence their everyday decisions. These kinds of research inquiries are not unique but the approach taken to design the study and to involve individuals with serious mental illnesses in the research process is likely to be very different.

Notwithstanding the above, much of the empirical work that has informed the knowledge base of evidence based practices for people with serious mental illnesses has been, and continues to be carried out by psychologists. Many of these studies have been randomized clinical trials that have been led by psychologists. This research has followed very traditional trajectories – only the topics and study population differ. Recovery oriented research may benefit from studies that are more qualitative in nature and design, including those that employ participatory action research methods.

Due to the difficulty of conducting complex community research with multiple variables that are difficult to control, and the need to obtain both quantitative and qualitative data, suggestions have emerged about how to move forward (Creswell, Klassen, Plano Clark & Smith, 2011; Tashakkori & Teddlie, 2003; Teddlie & Tashakkori, 2009) and involve the use of mixed methods designs. These suggestions seem particularly appropriate for our efforts to learn which interventions work best for people with serious mental illnesses. In mixed methods research, quantitative and qualitative data collection and analysis are combined in the same study, not in sequential processes, but as part of one overall design. The central premise of mixed methods research is that using quantitative and qualitative approaches at the same time provides a stronger design and a better way to view the research question and the study results than either approach alone. Combining quantitative and qualitative designs may be the approach of choice for studying the variables of interest in the recovery paradigm and PSR interventions. For additional information about mixed methods research, consult the Scientific Foundations module of this curriculum. Information can also be found in a publication from the NIH Office of Behavioral and Social Sciences Research which developed a guidance document aimed at helping potential grantees understand and use mixed methods research (Creswell, Klassen, Plano Clark & Smith, 2011).

### **Psychologists as Program Managers**

Psychologists often serve as team directors or team strategists where they lead implementation efforts and supervise staff who are delivering services. A recovery orientation involves a change in attitudes, values and beliefs, not only about the potential of people with serious mental illness, but also about the roles, responsibilities, and services offered by psychologists and other practitioners. The move to a recovery oriented system requires a paradigm shift and as with any paradigm shift, resistance is frequently encountered from staff who may be fearful of new ways of carrying out their duties and roles, and of what these changes mean for them. Psychologists who work in mental health systems that are changing to a recovery orientation must be prepared to assist staff, including other psychologists, confront the resistance they experience and work through

that constructively. Due to psychologists' training in group facilitation, psychologists are well suited to help staff understand the reasons that new ways of providing services can be beneficial to people with serious mental illnesses and help staff deal with the anxiety that surrounds change.

Thanks to the research training that psychologists receive, psychologists are also well suited to translate the research literature so that it is understandable and to highlight the relevance of scientific findings for the population being served. One way to accomplish this is to use the research behind evidence based practices and other empirically supported practices to inform staff about the improved outcomes demonstrated following their use and a recovery oriented philosophy of care. This can help staff to more easily see the benefit of new and different kinds of services. Psychologists are also trained to conduct program evaluations of new services and when these assessments indicate positive results, staff are more likely to see the benefits of the changes. Such evaluations serve another valuable purpose – when the evaluation results are not positive, programs and services can be revised to ensure that they are truly meeting the needs of the people they are intended to serve. Likewise, designing and implementing a performance monitoring system to track results and monitor progress is an essential component of this aspect of the change process. Developing monitoring systems is another skill most psychologists have and is one that system managers can use to facilitate systems change.

### **Psychologists as Administrators and Policy Makers**

Psychologists who serve in administrative and policy making roles have unique opportunities to effect system change. Increasingly, psychologists are serving as senior executives in governmental agencies and behavioral health organizations, and are being elected to political office at local, state, and federal levels. This presents unprecedented opportunities to lead the mental health service delivery system to a recovery oriented system that values and respects users of services. For those psychologists who have access to resources, an obvious place to start is by allocating funds and other resources needed to accomplish change and ensure successful implementation.

One challenge faced by psychologists in administrative and policy making positions is that these are relatively new roles that have not been traditionally occupied by psychologists. Psychologists have not traditionally embraced the worlds of politics and advocacy, preferring instead to work directly with people in need of clinical assistance. Thus, despite being in administrative leadership positions, many psychologists may not feel comfortable with, nor have the skills needed, to undertake system transformation, especially when that transformation is likely to evoke resistance from others within and outside the system. Changing systems of care and attendant practices requires knowledge of the practices to be implemented, leadership capability, political savvy, and, in some cases, great tenacity.

## **Health Care Reform: What's in it for People with Serious Mental Illness and How Psychology Can Help**

The Patient Protection and Affordable Care Act of 2010 (U.S. Public Law 111-148, 2010) and the subsequent amendments to it, the Health Care and Education Reconciliation Act of 2010 (U.S. Public Law 111-152, 2010) ushered in a new era for the provision of health care in the United States. In addition to the mental health parity legislation that was passed in 2008 (the Mental Health Parity and Addiction Equity Act of 2008), (Federal Register, 2013), the health care reform legislation of 2010 has many provisions that can ultimately benefit people with serious mental illness and that are of interest to psychologists. Many parts of the new law remain to be clarified and there will no doubt be challenges and changes. However, there are some immediately apparent benefits for people with serious mental illness and also for psychologists that can be identified. These are discussed below.

Changing mental health service delivery systems and changing the behavior of those who work in these systems will not be easy. In recent years, several attempts at changing systems have been made. While there have been some successes, change has proven difficult and many times, changes that were accomplished have been rolled back when new leadership and/or new clinicians entered the system. However, according to a recent report commissioned by the U.S. Agency for Healthcare Research and Quality:

The opportunities associated with health care reform are many, and business as usual, with its incremental efforts to improve outcomes, is no longer possible. Researchers, administrators, policy makers, and clinicians are at a crossroads. It is time to take on the challenge of producing learning systems that can provide real patient-centered and patient-directed care to individuals with serious mental illnesses (Green, Estroff, Yarborough, Spofford, Solloway, Kitson & Perrin, 2014, p xi).

### **Anticipated Benefits for People with Serious Mental Illnesses**

For people with serious mental illnesses, the new law, now referred to as the Affordable Care Act (ACA) or simply health care reform legislation, will significantly broaden the opportunities they have to obtain health insurance (Beronio, Po, Skopec & Glied, 2013). This is nothing short of monumental for individuals with serious mental illness who have traditionally been among the nation's poorest and most vulnerable groups. Currently, for people who are not insured through Medicaid or by an employer with 50 or more employees, it is very difficult to access affordable mental health services due to limitations in the Mental Health Parity and Addiction Equity Act and the failure of many states to adopt their own mental health parity laws. Under health care reform, these individuals will be able to obtain subsidies to purchase insurance if they cannot afford it, and it will not be possible to deny coverage due to a person's illness(es), even where those illnesses were pre-existing prior to enactment of the legislation. However, since the Act is new and states are able to "opt out" of the provision for receipt of subsidy funding, it may be that individuals

in states that choose to opt out will continue to lack access to coverage. This will need to be watched carefully (Garfield, Lave & Donohue, 2010).

An additional feature that will benefit individuals with serious mental illnesses and their families is that children will be able to be included in their parents' insurance plans until age 27. Since schizophrenia and other psychoses often strike young people in their teens and early twenties, the developmental trajectory of these young people is often altered resulting in an inability to complete educational plans and obtain sustained employment. Being maintained on their parent's health insurance while they work to recover will be a major boost to many of these young people.

For those people with serious mental illness that are working, their condition will no longer pose an impediment for their employer to provide coverage. In fact, employers will be required to provide coverage to everyone equally, as everyone will be entitled to, and in fact required to have, health insurance. All qualified health plans are now required to comply with the federal parity law, the Mental Health Parity and Addiction Equity Act of 2008, P.L. 110-343. This means that mental health and substance use benefits must be provided at parity with medical/surgical benefits in these plans (Federal Register, November 13, 2013).

A fundamental component of the legislation is that patient-centered, integrated primary health care should be available to all Americans. In addition to expanded access to health care, people with serious mental illness should realize other benefits as well, principally in the physical health domain. The legislation encourages accountable care organizations (ACO) and smaller-scale patient-centered medical homes (PCMH) as two models for comprehensive, integrated patient care led by primary care providers. ACOs contract with payers to provide a broad range of services to a designated population, with the goal of reducing costs while ensuring quality care. The PCMH model of care involves an interprofessional team of providers led by a personal physician delivering continuous and coordinated care to patients. Under these models, service delivery focuses on "whole person" care that recognizes the mind-body connection and the importance of integrating physical health services with mental and behavioral health services (American Psychological Association, 2012). People with serious mental illness often have substantial physical health problems and increased morbidity and mortality from those conditions. Since everyone will have access to general medical care, it is hoped that a good portion of these disparities will be reduced. Expanded benefits will apply to long-term care for supportive services and from improved coverage of preventive services in expanded health insurance plans.

One of the guiding principles of the new legislation is that all health care should be integrated and delivered by interdisciplinary teams and that consumers of that care should be seen as part of the team. This emphasis on integration of mental health care is to be achieved in the broader context of promotion of patient-centered treatment models. One model supported in the Act is the "medical home", which is a valuable means for

enhancing mental health treatment. Locating specialists – such as psychologists and other mental health professionals – in a primary care setting is seen as a potentially effective way to identify and manage multiple treatment needs and coordinate care. At the heart of this move is the concept of patient centered care. While not identical to the concept of recovery from serious mental illness, patient centered care is a step toward the recovery concept because it emphasizes the need to put consumers of care at the center and requires coordination with consumers and respect for their wishes. The leap from patient centered care to recovery oriented care in mental health is not difficult to make.

Examples of discrepancies that exist for people with mental health disorders can be seen from the following data. It is hoped the ACA will substantially reduce or eliminate these discrepancies:

- One in four uninsured adult Americans has a mental disorder, substance use disorder, or both (National Alliance on Mental Illness and National Council for Community Behavioral Healthcare, 2008);
- Mental illness is the leading cause of disability in the United States and Canada for people between the ages of 15 and 44 (World Health Organization, 2008);
- The Global Burden of Disease study indicates that the burden of disease from mental disorders for countries like the United States exceeds those from any other health condition (World Health Organization, 2001);
- Adults with serious mental illness die, on average, 25 years sooner than those who do not have a mental illness (National Association of State Mental Health Program Directors Medical Directors Council, 2006);
- In 2002, mental illness and substance use disorders led to \$193 billion in lost productivity – more than the gross revenue of 499 of the Fortune 500 companies – and by 2013, this figure is estimated to rise to more than \$300 billion (Kessler, 2008);
- Almost one in four stays in U.S. community hospitals involved depression, bipolar disorder, schizophrenia, and other mental health and substance use disorders (Agency for Healthcare Research and Quality, 2007).

### **How Psychologists can Help by Using the Research and Demonstration Provisions of the Act**

The healthcare reform legislation seeks to enhance mental health care in the United States by promoting evidence-based treatment of behavioral health conditions. As primary care providers, psychologists are vital in treating and preventing a range of health and mental health concerns in children, teens and adults. Like other healthcare providers, under the new law, mental health professionals will be asked to participate in more efforts to measure outcomes. This will offer psychologists the opportunity to demonstrate the value of the interventions they offer. This will also genuinely reform mental healthcare, as mental health providers are not accustomed to the level of scrutiny required by the new legislation.

The Act places considerable emphasis on provision of “evidence based medicine”. While this is often construed to mean interventions designed to affect physical health conditions, most believe that mental and behavioral health practitioners will be held to a similar standard, i.e., showing that what is provided for people with mental health disorders works and has positive benefits. The PSR interventions that help people recover and live satisfying and productive lives in the community are examples of evidence based medicine in mental health. Psychologists must be prepared to design, deliver, and evaluate them in their work settings. The legislation’s repeated emphasis on quality-of-care measures and on evidence-based treatment will increase the need for use of proven approaches in mental health care. PSR interventions are exactly the kind of proven services that may be required.

Thus, an exciting possibility that may be afforded by the demonstration grant provisions of the law is the opportunity to conduct research on the efficacy of the already identified evidence based and promising practices in less well-resourced environments. Resource limitations have often compromised fidelity to the original evidence based practices and have often been a stumbling block to their implementation. The demonstration grant provisions of the new law may also allow for the possibility of evaluating some practices that have not yet been designated as evidence based, and that may be better suited to provision in a less well structured community setting.

The legislation also affords the opportunity for grants to establish demonstration projects for the provision of coordinated and integrated services to adults with mental illnesses who have co-occurring primary care conditions or chronic medical diseases. These projects will deliver care through the co-location of primary and specialty care services in community-based mental and behavioral health settings. Demonstration grants will afford psychologists the opportunity to refine interdisciplinary models of care and demonstrate the value of incorporating behavioral health specialists in settings previously reserved for medically trained personnel.

The Act also provides funding for training psychologists to work with vulnerable populations, including those with severe mental health disorders. All of these opportunities open the door for psychologists to broaden the traditional scope of training and practice to incorporate people with serious mental illnesses.

In sum, the Act encourages mental health treatment services to be integrated into primary care settings and requires that providers use evidence based practices and demonstrate outcomes. Providers who use practices supported by evidence would be rewarded with greater public reimbursements and where insurance is part of the payment scheme, have more practice opportunities within private plans’ provider networks. All of this speaks to the need for psychologists to be appropriately and adequately trained to approach mental health care from a recovery perspective and to use evidence based PSR practices when these meet the needs and desires of the people they serve.

## Challenges

There are many challenges that lie ahead as the United States moves toward a system that provides increased access to health and mental health care for the majority of its citizens. These challenges are magnified by the fact that only the broadest of parameters have been established for the new system. Thus in some ways, the new system is a moving target for both users of the system and for providers. Some of the greatest challenges are discussed below.

For individuals with serious mental illness, the greatest challenge may be learning about and accessing benefits that the new law has to offer. This challenge will be faced by all citizens in the US and people with impairments of any kind need to be especially vigilant to ensure that the new benefits are made available to them. This may require advocacy on the part of individuals and by advocacy organizations.

For psychologists, the challenges may be more self-imposed than system imposed. For example, many psychologists will be reluctant to give up individual private practices to join interdisciplinary teams. Although this will not be required, the legislation encourages multi-disciplinary teams that are patient centered and utilize interventions supported by an evidence base. Improved outcomes for consumers must also be demonstrated. This may be a difficult change for psychologists who are used to practicing autonomously with little oversight or accountability.

Another challenge will be the incorporation of training for work with the most vulnerable populations, including those with serious mental illnesses, into traditional psychology training programs. Although some progress has been made toward this goal, most doctoral training programs currently pay scant attention to the most important aspects of this work, i.e., the recovery paradigm and PSR interventions. Most recently some have begun to argue that such training is needed if we are to adequately prepare psychologists to genuinely be of expert assistance to people with serious mental illnesses (Mueser, Silverstein & Farkas, 2013). Given the long established mentor system that exists in training programs, infusing new clinical and research concepts into training programs may meet considerable resistance and prove to be a major challenge. This curriculum is designed to help meet that challenge.

## Summary

Psychologists have worked alongside people with serious mental illnesses since the early days of the recovery movement in the mid 1970s to advocate for clinical and systems change by publishing first person and professional accounts, conducting research, and advocating for change.

Many psychologists have been involved in this effort and continue to work to support the changes needed to ensure that people with serious mental illnesses have hope, are treated with respect, and receive the services they wish to receive.



Psychologists occupy many different roles in academia, clinical settings, and mental health systems. These roles can be substantially different when viewed and carried out from a traditional perspective versus a recovery oriented perspective. The most typical roles that psychologists occupy include functioning as clinicians, researchers, program managers, and administrators and policy makers.

While the specific duties of each role vary widely, the overarching differences are that psychologists who approach their work from a recovery perspective work as a partner with people with serious mental illnesses rather doing to, or doing for, people with these illnesses. While it might not sound like a big difference, this is a huge philosophically different approach.

This means that clinicians conduct assessments that focus on strengths and skills, and only provide interventions that their clients have decided they want; researchers include consumers as equal partners in all phases of studies; program managers help staff understand the value of new, more functionally oriented services and of working with consumers rather than designing programs without their input and agreement; and administrators and policy makers accept the need to take on the risks and challenges that will likely come with system change efforts.

Health care reform legislation enacted over the course of the past few years offers the opportunity for unprecedented gains for consumers of mental health services. The Patient Protection and Affordable Care Act of 2010, its amendments, and the Mental Health Parity and Addiction Equity Act of 2008, hold promise for changing the way that people with serious mental illnesses access and receive services, and for changing the physical and mental health trajectory for individuals.

Health care reform offers the possibility for psychologists to be at the center of the process by conducting research demonstrations on new interventions, alternate venues for service delivery, and outcomes of new service models for people with serious mental illnesses.

In order for consumers and psychologists to truly benefit from the new legislation, psychologists must be adequately trained. This will require a paradigm shift in traditional training programs that have responsibility for imparting new attitudes, values and beliefs to the next generation of psychologists.

## Sample Learning Activity

This activity has two parts. The first part consists of watching a short video clip of a person with lived experience who works as a peer support worker. The link to the video is:

<http://vimeopro.com/createusmedia/samsha-cps-interviews/video/75881005> and the password is: NAPS2012\$SAMSHA

The second part of the activity consists of discussing the following questions:

1. What stood out for you in the clip and why?
2. How did you see some of the goals of “person-centeredness” play out in the clip? (e.g., hope, overcoming stigma/community inclusion, partnership, strengths-based)?
3. What did you learn?

## Sample Evaluation Questions

<u>Question</u>	<u>True</u>	<u>False</u>
1. Psychologists have had little impact on the recovery movement		X
2. A person with a serious mental illness has very limited vocational options and should never consider becoming a psychologist or other mental health practitioner		X
3. Psychologists who practice from a recovery orientation primarily conduct diagnostic and neurological assessment		X
4. Health care reform legislation holds promise of closing the early mortality gap between people with serious mental illness and those who do not have serious mental illness because those with such disorders will have equal access to physical health care	X	
5. Health care reform opens the door to train psychologists in behavioral health services for the most vulnerable populations	X	

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## Citing the Curriculum

Citation for this Module:

American Psychological Association & Jansen, M. A. (2014). The Recovery Movement: Role of Psychologists and Health Care Reform. *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

Citation for the full Curriculum:

American Psychological Association & Jansen, M. A. (2014). *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

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# American Psychological Association

## Recovery to Practice Initiative Curriculum: Reframing Psychology for the Emerging Health Care Environment

### ***3. Assessment***

August 2014

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## Overview

In this module of the course the topic of conducting recovery oriented assessments is discussed. The importance of focusing on strengths and taking a broad, contextual view of the world in which the person lives is presented. The differences between traditional clinical assessments and a recovery oriented assessment are discussed and examples of questions that can be used in a strengths based or recovery oriented assessment are provided.

## Learning Objectives

At the end of this module you will be able to:

- Describe at least three reasons why an assessment that focuses on a person's strengths is important
- Discuss at least four differences between traditional clinical assessments and strengths based, ecological, and functional assessments
- Identify five of the important components of strengths based, ecological and functional assessments
- Give at least six examples of questions designed to elicit a person's strengths, skills, resources and supports, skills to be developed, and cultural factors that may be important consideration for the recovery and rehabilitation process

## Resources

- Lecture Notes
- Required Readings
- Lecture Notes Citations
- Sample Learning Activity
- Sample Evaluation Questions
- Additional Resources

## Required Readings

Brun, C. & Rapp, R. C. (2001). Strengths-based case management: Individuals' perspectives on strengths and the case manager relationship. *Social Work*, 46, 3, 278–288.

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## Activities

Complete the following activities:

- Read the lecture notes
- Read the required readings
- Engage in a learning activity related to this module
- Evaluate students' understanding of this module.

## Lecture Notes

People with lived experience of serious mental illness are strongly encouraged to be part of the delivery of the curriculum including being active participants in the delivery of the lecture. Refer to the curriculum Instruction module for additional information.

### Introduction

When one considers that the overarching goal of recovery is attainment of a fulfilling and satisfying life in the community, the concept of assessment takes on a meaning that is considerably different from that which psychologists usually ascribe to the term.

Traditional clinical assessment can be a valuable addition to the psychologist's set of skills. For example it may be helpful to know a person's medical history, diagnosis (although this can sometimes also induce bias), distressing symptoms, medication use, etc.

Neuropsychological assessment may be especially useful because of the information about cognitive functioning that can be important when goals, skills, resources, and interventions are considered. However, as useful as these tools and the information they provide may be, they do not provide the most important information about a person with serious mental illness.

While the basic interviewing and assessment skills learned by every psychologist in the course of clinical training are helpful, the information most useful for helping a person recover from the oftentimes devastating effects of serious mental illness and achieve a satisfying life, is comprised of the individual's strengths, goals, skills and challenges, available resources, environmental context, experience of daily life, and the sociocultural factors that provide the context for his or her experiences (Davidson, Rowe, Tondora, O'Connell, et al., 2008; Pratt & Mueser, 2002). Indeed, Silverstein has stated:

The cornerstone of any good treatment plan is a thorough assessment of a person's strengths and weaknesses (Silverstein, 2000).

The focus of this module is on assessment of these important recovery and goal directed factors, rather than on the more traditional clinical assessments that psychologists are typically taught to conduct. As will be seen, the skills needed to conduct a recovery oriented assessment will build on, and be complimentary to the traditional skills learned by clinicians in the course of their graduate training.

### What are the Differences between a Clinical Assessment and Why is a Recovery Oriented Assessment Important?

Traditional clinical assessments, to a large degree, focus on a person's deficits: psychiatric diagnosis, problematic symptoms and behaviors, failures in social, educational and vocational pursuits, and difficulties experienced in living. Traditional clinical assessments rarely include questions about the circumstances of the person's life such as his or her living

situation, family dynamics, socio-cultural environment, and the context in which all of these occur. A traditional clinical assessment also rarely asks questions about the positive aspects of the individual or the person's life and generally do not emphasize the strengths, resilience, and accomplishments of the person. The focus of a traditional clinical assessment is on the person's illness and the ways this has negatively impacted the individual's life. This negative focus colors personal interactions and future service plans, focuses interventions solely on the individual, and reinforces an illness mentality (Slade, 2010).

Understanding a person's lived experience is crucial to assisting the person with the recovery process. In order to do this, many psychologists and other mental health practitioners now acknowledge that a more comprehensive and positive approach that looks beyond the individual and his or her symptoms and diagnosis is important for helping the person think about the future, decide what his or her goals are, what kind of life the person wants to have, and determine the best ways to achieve those goals (Brun & Rapp, 2001; Davidson, Rowe, Tondora, O'Connell, et al., 2008; Farkas, Sullivan Soydan & Gagne, 2000; Pratt & Mueser, 2002). This is after all, the way that most people approach the process of planning future goals: people use their strengths and successes to develop future aspirations and goals, and build on those strengths and successes to accomplish new goals.

A strengths based approach recognizes that every individual has capabilities, accomplishments and potential, and considers positive factors in the person's surrounding environment such as his or her natural support network including family strengths, community supports, and social service system network. These characteristics mean that each person has the potential for future accomplishments that will facilitate continuing to attain the life he or she wishes to achieve (Davidson, Rowe, Tondora, O'Connell, et al., 2008; Farkas, Sullivan Soydan & Gagne, 2000). An assessment based on a person's strengths and capabilities has been defined as:

Strength-based assessment is defined as the measurement of those emotional and behavioral skills, competencies and characteristics that create a sense of personal accomplishment, contribute to satisfying relationships with family members, peers, and adults, enhance one's ability to deal with adversity and stress, and promote one's personal, social and academic development (Epstein & Sharma, 1998).

In addition to gathering information about the individual's strengths, accomplishments, functional capabilities, and resiliencies, information is sought regarding resources within the individual's family, his or her support network, and community at large. Assessment is conceptualized broadly to include one's skills and talents, community and environmental resources, cultural knowledge and lore, knowledge gained from struggling with adversity, as well as knowledge gained from educational or occupational endeavors. Information from each assessment is shared openly with the individual and his or her family, when the person has given consent for information sharing with the family and or others (Tondora, 2011). A strengths based approach recognizes that every individual, no matter how severe

the person's illness might be, has the capacity to continue to learn and develop (Davidson, Rowe, Tondora, O'Connell, et al., 2008). Competency-building and promoting mental wellness are complementary approaches that should be used in conjunction with treatment interventions (Miles, Espiritu, Horen, Sebian & Waetzig, 2010).

Determining an individual's strengths and capabilities is important for children and young people as well. The Outcomes Roundtable for Children and Families (a consortium of researchers, youth, family members, providers, and policymakers) identified important outcomes that all families want for their children, and noted that families seeking services for children with mental health concerns want services that promote the development of competencies, and functional lifetime outcomes. This focus transcends symptom reduction, and goes beyond reduction of deficits (Bellonci, Jordan, Massey, Lieberman, Zubritsky & Edwall, 2012).

Some examples of strengths that mental health practitioners might not immediately consider include:

- Skills (e.g., gardening, caring for children, speaking Spanish, doing budgets)
- Talents (e.g., playing the bagpipes, cooking)
- Personal virtues and traits (e.g., insight, patience, sense of humor, self-discipline)
- Interpersonal skills (e.g., comforting others, giving advice, mediating conflicts)
- Interpersonal and environmental resources (e.g., extended family, good neighbors)
- Cultural knowledge and lore (e.g., healing ceremonies and rituals, stories of cultural perseverance)
- Family stories and narratives (e.g., migration and settlement, falls from grace and then redemption)
- Knowledge gained from struggling with adversity (e.g., how one came to survive past events, how one maintains hope and faith)
- Knowledge gained from occupational or parental roles (e.g., caring for others, planning events)
- Spirituality and faith (e.g., a system of meaning to rely on, a declaration of purpose beyond self)
- Hopes and dreams (e.g., personal goals and vision, positive expectations about a better future) (Saleeby, 2001).

A strengths based approach to assessment that encompasses the person's environmental context is sometimes referred to as an ecological assessment. In addition to looking at an individual's strengths, resiliencies, and capabilities, the environmental factors that affect the person's everyday living situation are taken into account (Rapp & Goscha, 2011). The continual process of seeking information would include obtaining information about

environmental factors in the person's life that may affect progress toward goals, skills and resources needed to accomplish goals, and eventually, the potential need to modify original goals and objectives. The more open and real a psychologist is, the more likely the sessions are to be successful, thereby requiring fewer changes later and assisting the person to be more open and honest with and about him or herself.

From an ecological perspective, to fully know and understand a person it is important to look at the individual's personal characteristics, information about his or her environment, and the pattern of interactions the person has within his or her environment (Wilson, 2004). An ecologically considered assessment works to formulate comprehensive information about the daily routine of a person's life, including asking such questions as "What is a typical day like for you?", "What is it like for you at work (or school)?", "What is it like to live in your neighborhood?", and "What has it been like for you when someone says, 'I'll help you'?" (Munger, 2000; Wilson, 2004).

Information for this broader assessment should be gathered about several life domains including living situation, educational and vocational accomplishments and aspirations, socialization and leisure, health status, financial and legal situation, and everyday circumstances in such realms as independent living, transportation, money management, etc. The assessment process should be one of two equal partners gathering information for future work together rather than one person (the mental health practitioner) delving into the life of another person (the person with an illness) (Elder, Evans & Nizette, 2009).

Taking a broader ecological perspective allows the psychologist to gain an understanding of the "fit" between the person and his or her environment so that they can work together to mobilize strengths and resources, and develop the skills and resources needed to facilitate recovery. When combined with a traditional clinical assessment, the broader focus on strengths, abilities, and environmental factors that influence the person's life allows a focus on understanding how advances can be made in the context of the person's life situation. Instead of focusing on problems and deficits, the focus shifts toward an exploration of clients' abilities, talents, and resources that are available to facilitate recovery (Brun & Rapp, 2001; Gray, 2011; Saleeby, 2008).

## **The What and How of Conducting a Strengths Based Assessment**

Conducting a strengths based assessment is very different from conducting a clinical assessment. Psychologists are typically well taught in the ways of clinical assessment; assessing an individual from a strengths perspective requires a very different approach and this is especially important when the person has a cultural background that is different from the majority.

### **Potential Impact of Culture on Assessment and Service Planning**

The impact of a person's cultural background can have profound effects on many areas of a person's life. Cultural factors, including religion, beliefs about mental illness, its etiology,



and its acceptability may influence the assessment process. The beliefs and values that a person is taught and grows up with may have considerable influence on the ways behavior is viewed, acceptability of seeking mental health services, and ability of women and children to speak for themselves, establish goals, determine skills they wish to develop, etc. Language barriers can have a profound effect on ability to communicate the many important facets of a person's life and background that impact on the assessment and planning process. In some cultures, it could be very difficult for an individual to participate actively in the planning process and take part in determining the future direction for his or her life.

The Diagnostic and Statistical Manual of Mental Disorders (DSM) is not a recovery oriented manual but the DSM IV's Outline for Cultural Formulation and the DSM 5's Cultural Formulation Interview offer some questions that can be used as a guide for helping to understand the person and his or her contextual life and experiences. The questions should not necessarily be asked verbatim but can be used as a guide to topics that may be relevant and the questions should be phrased to reflect sensitivity to the person's background and culture. Not all of the questions will be relevant to every person or in every situation. The examples below may be the impetus for additional discussion about the person's background and cultural experiences and can spark additional discussion as opportunities arise:

#### I. Cultural identity of the individual:

- What is your ethnic background?
- In what ways do you identify with your cultural group in your daily life? For example, in types of food you eat, clothing you wear, rituals you follow during the week and on holidays?
- In what ways did your family of origin identify with your cultural group in your daily life growing up?
- In what ways do you identify with mainstream American culture in your daily life?
- What languages do you speak? Which did you speak growing up? Which do you prefer to use now, and in what situations?
- For immigrants: What kind of job did you have in your country of origin? What kind of job do you have now? What was the impact of immigration on your and your family's financial situation and professional status?
- For immigrants: What were your (or your family's) reasons for immigrating? What were the circumstances of the immigration? (note any dangers involved)

#### II. Cultural explanations of the individual's illness:

- What has been your past experience with mental health professionals?
- What other kinds of help have you sought?

- What words do you and your family use to describe symptoms ("idioms for distress")?
- What is the meaning of the symptoms in relation to norms of your cultural reference group?
- How does your family explain your symptoms?

### III. Cultural factors related to psychosocial environment and levels of functioning:

- What kind of stressors have you been experiencing?
- What kinds of social support are available?
- What religious or other support systems are available?
- How do the symptoms impact your functioning? (American Psychiatric Association, 1994; American Psychiatric Association, 2013).

The questions below can be used to enhance the psychologist's understanding of how culture and background influence the perception of the mental health problem:

- What do you call your problem? What caused it? Note: the answer has everything to do with the cultural filters of the person in recovery and can provide you with rich information and possible avenues for discussion of recovery support networks.
- Whom do you include as family? Whom do you trust? Note: these are the people who may form the person's recovery support network.
- Have you ever been a member of a faith community? Note: this is important because many people believe that God has turned a blind eye when they become ill or develop chemical dependency problems and they cease involvement with church, synagogue, mosque or other religious communities.
- Are you a member of a faith community now? If so, would you like the Rabbi, Priest, Pastor, Imam, etc. to be part of and involved in your support network? If not, why not? Note: it is a rare clergy member who will not participate as best he/she can when called.
- Are you now going, or have you ever gone, to an Indigenous Healer for help with your problem? Would you like that person involved as part of your recovery support network? Note: this question is especially relevant for Native people, Latinos and people of African origin.
- With whom do you have intimate relations and relationships? Note: this way of asking about sexual orientation is a bit more sensitive than asking a person's sexual orientation outright.
- Have you ever experienced racism, police brutality, discrimination and/or other forms of oppression? Note: expect a wealth of clinical information from this

question, if not initially, information will be likely to be forthcoming as a trusting relationship develops.

- How do you identify culturally/racially/ethnically? Note: mental health practitioners tend to make assumptions about people based on their outward appearances and often, those assumptions are incorrect.
- What do you know about your culture? What holidays do you observe? Are they related to your culture?
- Has your family always lived in this area? Note: this question can elicit histories of emigration and immigration, as well as issues such as sharecropping in families of African origin, migrant workers, etc.
- What were the messages about your culture that you received while growing up? What were the messages you received about the cultures of others? Note: issues such as self-hate, ethnic privilege and discrimination, reverse and internalized racism, etc. surface with this question (Ali, 2011).

### **Some Practical Issues and Suggestions for Conducting the Assessment**

It is important to remember that each person is the most knowledgeable about him or herself and therefore the best expert about his or her history, significant life events, accomplishments, skills and skill deficits, motivating as well as crushing forces, achievements, preferences, available resources, etc. An in-depth discussion with the person, asking directly about the things that are important to that person, is usually the best way to learn about the person.

A strengths based assessment will explore the whole of peoples' lives while ensuring emphasis is given to the individual's expressed and pressing priorities. For example, people experiencing problems with mental illness or addiction often place less emphasis on symptom reduction and abstinence than on desired improvements in other areas of life such as work, financial security, safe housing, child care, and relationships. It is essential to explore each person's needs, desires, and available resources, in detail, in all areas to be sure that that the person's true priorities are ascertained (Davidson, Rowe, Tondora, O'Connell, et al., 2008; Farkas, Sullivan Soydan & Gagne, 2000; Pratt & Mueser, 2002; Rapp, 2001). For those that have had the opportunity to develop one, a Wellness Recovery Action Plan (WRAP) (Copeland, 2002) can be a highly useful tool from which helpful information can be gleaned.

Despite psychologists' excellent training as clinicians which typically encourages use of clinical language, it is best to record the individual's responses as he or she gives them rather than translating the information into professional or clinical language. By keeping the responses authentic, they remain a true record of the person's thoughts and feelings. Additionally, there will always be a record of the person's actual responses which can become very useful when questions come up later about why something was said or done.

In addition to gathering information about the things considered most important to an individual, it is important to gather information about the person's functional capabilities. As part of a functional assessment, questions are asked about the person's current skills and capabilities and also about the skills needed to achieve the life goals he or she wishes to achieve. An assessment of available resources is also needed to determine the supports available to help in achieving the person's goals (Farkas, Sullivan Soydan & Gagne, 2000).

Some suggestions for topical areas that can be covered and questions that can be asked of the person and of his or her family/support network include the following. Note – a creative way to explore these is to write the questions on a card and have the person read and think about them. This avoids the question and answer drill that can be off-putting and can lead to more thoughtful responses:

- Personal strengths: e.g., What are you most proud of in your life? What is one thing you would not change about yourself? What are your best qualities? What are some of the traits people mention when they talk about you? What are one or two things that you see as making you different and unique from others? What makes you smile?
- Interests and activities: e.g., If you could plan the "perfect day," what would it look like? What do you care about? What matters to you? Name three things that you occasionally look forward to? What dissatisfies you about your life? What do you wish you could change?
- Living environment: e.g., What are the most important things to you when deciding where to live?
- Employment: e.g., What would be your ideal job and why? What skills do you have, for example, artistic or athletic talents, technological expertise, leadership, capacity for work? Think back to before you first began to struggle with the illness, what did you dream of being when you grew up – tell me about it?
- Learning: e.g., What kinds of things have you liked learning about in the past?
- Trauma: e.g., In relationships with other previous or current therapist(s), doctor(s), friends, family, other consumers, teachers, or anyone else, have you ever been treated inappropriately or in ways that were harmful to you (e.g., poor boundaries, sexual inappropriateness, physical abuse, taunting, bullying, etc.)?
- Safety and legal issues: e.g., Do you have any legal issues that are causing you problems?
- Financial: e.g., Would you like to be more independent with managing your finances? If so, how do you think you could do that?

- Lifestyle and health: e.g., Do you have any concerns about your overall health? What are those concerns? Tell me a bit about your mental health: What does a good day look like? A bad day?
- Choice-Making: e.g., What are the some of the choices that you currently make in your life? Are there choices in your life that are made for you?
- Transportation: e.g., How do you currently get around from place to place? What would help?
- Faith and spirituality: e.g., What type of spiritual or faith activities do you participate in? How do you find meaning in your life? Where and when do you feel most at peace?
- Relationships and important people: e.g., Who is the person in your life that believes in you? In what ways does this person convey this belief in you? To what degree is your family, spouse, or significant other available to provide support for you?
- Hopes and dreams: e.g., Tell me a bit about your hopes or dreams for the future? What you are seeking? What are your goals for yourself?
- Resilience: e.g., What would you say are indicators of your resilience; for example, the attributes of intelligence, sense of humor, optimism, creativity? What helps you get through the day? What are your greatest strengths? What has helped you in the past?
- Mental health treatment: e.g., What can the staff do to help? What can you do to help? Who else can help? What services do you want? What, if any, do you want to avoid? What do you hope to accomplish from mental health treatment?

Topics that can be discussed with the person's family/support network (with the person's permission):

- What type of support, resources, or assistance are you or other members of the person's support network (current family, spouse, or significant other) able to provide for the person? What would you say about the people in his or her support network in terms of their ability to be helpful, supportive, and communicative? Are there any concerns or limitations that come to mind?
- Would you say the family is resilient, for example, have affirming belief systems, facilitative organizational patterns, and positive communication processes? (Ashenden, 2008; Gray, 2011; Tondora, 2011).

## Structured Assessment Instruments

As of this writing, there are no strictly strengths based or ecological assessments for adults that are readily available in the published literature. There are however three published assessment instruments that were designed for use with people who are living with a

serious mental illness that incorporate a strengths perspective. Psychologists who will be conducting assessments with people with serious mental illness may want to review these instruments and combine aspects or the entire instrument with the questions listed in the previous section to form a comprehensive assessment package. The three structured assessments are:

1) *The Client's Assessment of Strength, Interests, and Goals (CASIG)* (Wallace, Lecomte, Wilde & Liberman, 2001)

The CASIG is a structured interview that the authors describe as follows: the "CASIG makes consumers active directors/collaborators in planning their own treatment, and the inclusion of their perspectives and those of the informants via parallel versions of the test increases communication among stakeholders" (Wallace, Lecomte, Wilde & Liberman, 2001). The CASIG asks the individual about his or her goals in five areas of community living: housing, money/work, interpersonal relationships, health, and spiritual activities. Additional questions are posed about the person's goals and the person is asked to identify the services he or she thinks would be needed to achieve them. Other questions ask about current and past community functioning, medication compliance and side effects, quality of life, quality of treatment, symptoms, and performance of intolerable community behaviors. A review of assessment instruments by Silverstein (2000) indicated that the CASIG includes: "(a) numerous areas essential to community living, (b) its results are directly relevant for treatment planning, (c) it can be repeatedly administered to assess progress, and (d) it focuses on goals and skills as well as symptoms and behavioral or cognitive difficulties."

There are now two additional versions of the CASIG, a self-report version, the CASIG-SR and an informant version, the CASIG-I (Lecomte, Wallace, Caron, Perreault, et al., 2004).

2) *The Independent Living Skills Inventory (ILSI)* (Menditto, Wallace, Liberman, Vander Wal, et al., 1999)

The ILSI is designed to measure a person's ability to perform skills needed for successful community living. The ILSI rates items on two dimensions: one, the degree to which the skill can be performed, and secondly, the degree of assistance required to perform the skill. According to Silverstein (2000) "This scoring method is useful in planning a rehabilitation program because it distinguishes between skills deficits and performance deficits, each requiring different forms of intervention."

3) *Psychiatric Rehabilitation Training Technology: Functional Assessment* (Cohen, Farkas & Cohen, 1986; 2007)

The functional assessment is designed to gather information about a person's skills and capabilities in relation to the person's goals. The authors state:

Functional assessment is developing an understanding of a person's functioning in the critical skills needed to be successful and satisfied in a particular environment. The

functional assessment evaluates individuals' spontaneous use, prompted use, and performance of critical skills in relation to their needed use. This technology teaches practitioners how to help define and evaluate the skills needed for consumers to be successful and satisfied in particular residential, educational, vocational, or social environments. Practitioners learn how to list critical skills, describe skill use, evaluate skill functioning, and coach individuals through the assessment process. An evaluation of the individual's present ability to use these skills is then completed (Cohen, Farkas & Cohen, 1986, 2007).

## **A Final Consideration**

At the conclusion of the initial assessment and after each successive assessment which takes place throughout the service delivery process, it is important to communicate to the person that his or her individual preferences, needs and values are respected. Throughout the process the person is assisted in identifying the next steps to move toward achieving his or her personal goals and choosing from among possible options. It is important to ensure the person understands what to expect from any treatment and make sure the treatment and other plans can be clearly linked to the person's recovery goal, and provide tools and resources that support and empower the person to take the next steps (Ashenden, 2008).

## **Challenges**

Perhaps the greatest challenge for conducting recovery oriented assessments comes from psychologists themselves and the training received in traditional clinical assessment courses. Learning to conduct comprehensive ecological, functional, strengths based assessments requires a paradigm shift that is fundamental to the concept of recovery, i.e., the notion that people with serious mental illness have considerable resilience and strengths that can be used to build successive accomplishments and that psychologists and other mental health practitioners are partners in helping to enhance the skills and resources already inherent in each person.

This is a new way of thinking about and working with people who have serious mental illness and may be challenging for psychologists who are often trained to view people with such illnesses as individuals who have few residual strengths and little potential for leading a satisfying life. This shift in thinking also requires a different set of tools and techniques from those typically learned by psychologists. Accepting and using these new methods may pose considerable challenges.

## **Summary**

Helping people with serious mental illness recover and achieve a satisfying life in the community requires a way of thinking about and conducting assessments that is different from the traditional clinical assessment methodology that psychologists are typically trained to conduct. Helping people recover and lead the life they desire requires

assessments that are comprehensive, based on strengths and functional capabilities, and encompass the full environmental context in which people live. A strengths based approach recognizes that every individual has capabilities, accomplishments and potential, and considers positive factors in the person's surrounding environment such as his or her natural support network including family strengths, community supports, and social service system network.

When conducting assessments that are strengths based, psychologists work directly with the person involved to gain detailed information from his or her perspective. The information gathered covers the person's goals, accomplishments, skills and perceived needs, living situation and environmental context, and desires for assistance from the mental health system. The person's family and support network form an important part of the person's contextual situation and, as directed by the person, are also asked to provide information. Cultural values, beliefs and the background of the person and his or family can play an important role in how mental health problems and treatments are viewed; this information is also critical in informing the assessment and planning process.

Assessments are completed whenever goals are achieved or missed to determine the person's perspective on the process and to decide if new or revised goals should be set. Information from the assessment process is always shared with the person and his or her support network so that transparency and openness are maintained within the bounds of confidentiality considerations. The assessment process is a partnership rather than a clinical undertaking where one person is in charge of the other.

A wide array of questions can be used to comprise the strengths based assessment and these can be combined with standardized assessment instruments to form a comprehensive array that will be informative to the person, his or her family and support network, and to the psychologist or other mental health practitioner. The full set of assessment questions can be tailored to best suit the needs of each individual person.



## Sample Learning Activity

There are two parts to this exercise. First, divide the large group into small groups of 4 – 5 persons. In each small group, each person is to share with the group one personal strength that helps that person in his or her work. Each person is also to share one personal challenge. Next, each person is to share one or more stereotype(s) that the individual has faced in his/her life. The group is to list and discuss if there is time, the stereotypes that people with serious mental illness typically face.

As always, confidentiality of information shared is paramount. No personal information should be shared with anyone who is not part of the class and discussions about personal information that may have been disclosed in the class should not occur outside the classroom. Information that is shared should never be used to affect an individual's status in the program.

With the responses from the first part of the activity in mind, each group is to work on the second part of the activity, as follows. The table below has 6 domains that the group is trying to assess. For each domain, choose a problem-focused question and as a group, for each question come up with a way to ask for the same information that is strength based.

Domain to Assess	Problem-Focused Questions	Strength-Based Question
<i>Example</i>	<i>"Why have you been truant twice a week for the last month?"</i>	<i>"How is it that you were able to make it to school on time, all day for three days a week for the last month?"</i>
<b>Family</b>	<i>"Does your family have a history of violence?"</i> OR <i>"Has anyone in your family ever been to jail or prison or been on probation?"</i>	
<b>Peers</b>	<i>"How much alcohol and drugs are your friends doing?"</i> OR <i>"Do you have any friends in a gang?"</i>	
<b>School/ Work</b>	<i>"Why are you failing this class?"</i> OR <i>"Why haven't you been able to get a job yet?"</i>	
<b>Drugs</b>	<i>"Do you think you have a drug problem?"</i> OR <i>"Why do you think you are using drugs so much?"</i>	
<b>Mental Health</b>	<i>"Have you ever been in therapy; why?"</i> OR <i>"Are there any areas of your life that are troubling you, that you worry about, or feel very sad about?"</i>	
<b>Citation</b>	<i>"Didn't you realize that you would get into this kind of trouble if you did _____?"</i>	

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## Sample Evaluation Questions

### Question

### Correct Answer

1. The differences between a clinical assessment and a strengths based assessment are:

- a) Clinical assessments focus primarily on deficits while strengths based assessments focus primarily on potential
  - b) Clinical assessments emphasize skills while strengths based assessments emphasize the possibilities that medications offer
  - c) Strengths based assessments usually incorporate the context in which people live where clinical assessments usually emphasize medically oriented aspects of a person's life
  - d) none of the above
  - e) a and c above
- e) is the correct answer

2. Which of the following statements are true?

- a) Input from a person's family can be useful but is generally not considered important because it is the person in recovery that the psychologist is endeavoring to help
  - b) Questions about a person's culture and background should not be part of the assessment because these are private and assessments should focus on strengths and capabilities
  - c) Although language can be a potential barrier, English is the official language of the United States, and therefore all assessments should be conducted in English
  - d) none of the above
- d) is the correct answer

3. A functional assessment:

- a) is used to assist the person in deciding appropriate goals and outlining the steps needed to achieve those goals
  - b) is only appropriate when an individual has a desire for social or vocational skills training
  - c) focuses on a person's strengths and includes components such as skills and capabilities, family support, educational and vocational history, and symptoms that affect functioning
  - d) all of the above
  - e) none of the above
- e) is the correct answer

True

False

4. A discussion of strengths should be a central focus of every assessment and case summary

T

5. Strengths-based assessment means focusing solely on strengths and capacities and does not include discussing the person's needs

F

## Lecture Notes Citations

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## Additional Resources

American Psychological Association Recovery to Practice Initiative.  
<http://www.apa.org/pi/rtp>

## Citing the Curriculum

Citation for this Module:

American Psychological Association & Jansen, M. A. (2014). Assessment. *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

Citation for the full Curriculum:

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# American Psychological Association

## **Recovery to Practice Initiative Curriculum: Reframing Psychology for the Emerging Health Care Environment**

### ***4. Engaging People as Partners in the Design, Delivery, and Evaluation of their Mental Health Services***

August 2014

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## Overview

In this module of the course we will discuss the issues that many people with serious mental illness face as they consider becoming involved with the mental health service delivery system, the ways that psychologists can help to overcome these challenges and facilitate engagement, and the benefits of partnering with people with serious mental illnesses.

## Learning Objectives

At the end of this module you will be able to:

- Describe four reasons for engaging people fully in their service planning, implementation and evaluation decisions
- Explain at least four reasons why it can be difficult for many people to engage with the service delivery system
- Describe at least three potential interventions that might help people with barriers to engagement overcome the issues they face
- Discuss at least three the benefits of becoming full partners with people with serious mental illness in all facets of the mental health service delivery system
- Describe at least four challenges faced by systems and providers and discuss ways that these challenges can be overcome
- Discuss three practices that result from what has been learned in this module

## Resources

- Lecture Notes
- Required Readings
- Lecture Notes Citations
- Sample Learning Activity
- Sample Evaluation Questions
- Additional Resources

## Required Readings

Birman, D., Ho, J., Pulley, E., Batia, K., et al. (2005). *Mental Health Interventions for Refugee Children in Resettlement*. [White Paper II]. Chicago, IL: National Child Traumatic Stress Network, Refugee Trauma Task Force.

Davidson, L., Tondora, J. S., Staeheli, M. R., O'Connell, M. J., Frey, J. & Chinman, M. J. (2003). Recovery Guides: An Emerging Model of Community-based Care for Adults with Psychiatric Disabilities. In A. Lightburn & P. Sessions (Eds.). *Community Based Clinical Practice*. London: Oxford University Press.

Tait, L. & Lester, H. (2005). Encouraging user involvement in mental health services. *Advances in Psychiatric Treatment*, 11, 168-175.

## Activities

Complete the following activities:

- Read the lecture notes
- Read the required readings
- Engage in a learning activity related to this module
- Evaluate students' understanding of this module.

## Lecture Notes

People with lived experience of serious mental illness are strongly encouraged to be part of the delivery of the curriculum including being active participants in the delivery of the lecture. Refer to the curriculum Instruction module for additional information.

### Introduction

Despite concerted efforts to assure that all who need mental health services receive them, most adults and children with mental health problems still do not receive the services they need (McKay, Hibbert, Hoagwood, Rodriguez, et al., 2004; National Institute of Mental Health, 2001; President's New Freedom Commission on Mental Health, 2003; U.S. Department of Health and Human Services, 1999; Wang, Lane, Olfson, Pincus, et al., 2005; Young, Klap, Sherbourne & Wells, 2001). There are many reasons why people who need mental health services do not receive them. Some of these involve limited availability of services, the costs of child care or transportation, and other more pressing problems such as lack of shelter or poor physical health. Some reasons involve a person's reluctance to engage in services because of prior negative experiences with the mental health system or cultural factors that make accessing services difficult.

Engaging people who have serious mental illnesses as true partners in the design, delivery, and evaluation of the mental health services they receive has been shown to be an important step in helping to improve access to services and to assure the efficacy of those services. Research has shown that individuals who are engaged and expect services to be effective benefit more from those services (Blatta & Zuroff, 2005; Cosden, Ellens, Schnell & Yamini-Diouf, 2005; Howgego, Yellowlees, Owen, Meldrum & Dark, 2003; Marsh & Fristad, 2002; Meyer, Pilkonis, Krupnick, Egan, et al., 2002); this is also true for individuals receiving services for co-occurring disorders such as substance abuse (Fiorentine, Nakashima & Anglin, 1999; Santisteban, Suarez-Morales, Robbins & Szapocznik, 2006).

This module will focus on the barriers that influence a person's willingness to access services. The benefits of engaging people in a true partnership are explored and suggestions are offered for ways to engage people despite the barriers they face.

### Some Reasons Why People Do Not Engage with the Mental Health System

There can be many reasons why people do not become involved with the mental health service delivery system. Some of these emanate from the system itself while others arise from the individual, either due to prior experiences or fears about what might come next.

#### Prior Negative Experiences

Some people with serious mental illnesses have had very bad experiences with the mental health system and many have been traumatized by these experiences. Individuals have

experienced long term, forced hospitalizations, forced medication administration, and abusive care within the mental health system itself. Some non-forensic and non-corrections hospitals in the U.S. still require people admitted for inpatient mental health care to disrobe and be examined for weapons, drugs, etc. In these environments, the practice is employed without regard to previous history of violence, abuse, or drug use. This is but one example of an experience that can be highly traumatizing, especially for someone who may be psychotic and already terrified due to the frightening auditory inputs and visual sights they are experiencing. Other negative experiences can range from emotional abuse by staff, to unsanitary psychiatric wards, to receipt of poor services that raised expectations but did little to help the person regain a satisfying life.

Experiences such as these leave individuals with little desire to engage with mental health services, even when new services are offered. Psychologists have a very serious responsibility to ensure that services and systems act responsibly, ethically, and do not add to the trauma often experienced by people with serious mental illnesses.

### **People with Multiple, and Often, Long Term Needs**

In addition to those who may have had prior negative experiences of the mental health system, there are some people who have difficulty accepting services due to the severity of their illness. Some individuals have multiple, long term barriers and may be unable to accept services because they are overwhelmed by the needs they face. These individuals are often, though not always, poor, may be homeless, have severe and untreated mental illness, substance use problems, criminal histories, be in ill physical health, and be socially stigmatized. Many have poor social skills, and are socially isolated. For this group of people, their mental health problems may be seen as the least of their worries. People with multiple problems need a range of basic services and they need support for everyday living, along with intensive help to access services across a range of agencies. Some of the services needed include income and housing supports, help with leisure and social pursuits, general medical care, and help with daily living activities. These are in addition to mental health care (The Sainsbury Centre for Mental Health, 1998).

One issue that remains disputed even within the mental health consumer community is that of forced medication use. Some of those who have written about the need for medication use when an individual is experiencing severe symptoms and unable to provide rational consent argue that it is in the individual's best interest to be forcibly administered psychotropic medications (Frese, Stanley, Kress & Vogel-Scibilia, 2001). Others have taken the opposite view and argued that psychotropic medications should not be administered against a person's will (Chamberlin, 2002). There are many views on both sides of this issue. Given that it remains under discussion, it is highlighted here simply as an issue to be aware of that may impact on a person's willingness to engage in services.

## **Cultural Factors and Issues for People Who Are Immigrants and or Refugees**

It has been estimated that 92% of immigrants and refugees in need of mental health services never receive them (Birman, Ho, Pulley, Batia, et al., 2005; Ellis, Lincoln, Charney, Ford-Paz, et al., 2010; Kataoka, Zhang & Wells, 2002). There are many reasons for this which have recently been articulated by Ellis, Miller, Baldwin & Abdi (2011), and include the following: “(a) distrust of authority and/or systems, (b) stigma of mental health services, (c) linguistic and cultural barriers, and (d) primacy and prioritization of resettlement stressors” (p. 70).

The influence of a person’s culture, background, religious beliefs, and or upbringing are important considerations that are often overlooked, but may have a profound impact on a person’s or a family’s willingness to engage in mental health services. These factors are becoming more apparent as the population becomes increasingly heterogeneous. Cultural factors, including religion, beliefs about mental illness, its etiology, and its acceptability, views regarding a person’s right to make choices as opposed to having those choices made for him or her, and language barriers, to name just a few, can substantially impact on the person’s acceptance of mental health problems and need for services.

In some cultures, the concept of mental illness is virtually non-existent because behaviors are considered to be under the control of spirits or other forces that can be controlled by indigenous healers or faith based providers (Constantine, Myers, Kindaichi & Moore, 2004; Malarney, 2002). Even where mental illnesses are seen as true illnesses, stigma may be so great that seeking or accepting mental health services is extremely difficult if not impossible.

There are many cultures in which young people do not ordinarily make decisions or choices for themselves but defer to the wishes of their elders (Ellis, Lincoln, Charney, Ford-Paz, et al., 2010; McKay, Hibbert, Hoagwood, Rodriguez, et al., 2004). Similarly, some cultures do not afford women the opportunity to express opinions or make decisions, reserving these for male members of the family (Said-Foqahaa, 2011). In such cultures, it could be very difficult for the person with mental health problems, and particularly with serious mental illness, to access services, participate actively in the planning process, and take part in determining the future direction of his or her life.

Another cultural issue that is not often discussed involves trauma resulting from family perpetrated physical or sexual abuse. Although this occurs in many cultures, it is not officially sanctioned. However, in some cultures women and sometimes children are seen as property to be used as desired (Chaudhuri, 2005; Said-Foqahaa, 2011), and these practices may be overlooked or unofficially sanctioned. This is rarely discussed and leads to tremendous trauma for the victim and sometimes for the perpetrator as well.

Language barriers also have a profound effect on one’s ability to communicate the many important facets of a person’s life and background that may have contributed, and may still contribute to the mental health problems experienced. In some languages, words or expressions used to describe aspects of mental illness do not exist. When combined with

the stigma of behavioral problems, it can be extremely challenging to help people explain the problems they are experiencing and engage in services.

Although examples such as those above are not often seen in the U.S., there are many recent immigrants from societies where the above examples are prevalent. Sensitivity to individuals from different backgrounds is essential if steps toward engaging an individual and his or her family are to be successful. In such cases, greater attention to family beliefs and preferences should be considered primary while attempting to involve the individual to the greatest extent possible and facilitate planning, service delivery, and ultimately recovery on the person's and family's terms. It is essential that services are available in multiple languages and from the cultural perspective of the person represented. In all cases, the person's wishes about culturally influenced choices must be respected.

An issue that has become more apparent in the last decade concerns the detention of immigrants by U.S. Immigration and Customs Enforcement (ICE). According to recent reports, over 350,000 immigrants are detained each year. An unknown percentage of these have a serious mental illness and are taken into custody despite a criminal court finding that they should not be detained but require inpatient mental health treatment. In ICE detention centers, jails or prisons where they are often sent, these individuals frequently are not provided assessment or medication, receive little care and are often segregated in isolation, further exacerbating their mental illness (Venters & Keller, 2012). When added to the multitude of problems faced by immigrants with serious mental illnesses, these individuals experience severe trauma and have little hope of achieving a successful transition to American life.

The experience of refugees deserves additional discussion. In addition to the multitude of problems experienced by immigrants and other newcomers, most refugees have endured extreme abuse at the hands of those in authority (Birman, Ho, Pulley, Batia, et al., 2005; Ellis, Miller, Baldwin & Abdi, 2011). As a result, refugees generally do not trust people in authority or those who work in institutions or systems where the rules and procedures are determined by someone seen as having power. Refugees typically experience extreme fear of those around them and perceive that they and their families are in imminent danger. When all of these factors are combined (stigma from original background, language barriers, religious beliefs about the origin of mental illness, cultural beliefs or practices related to decision making and or sexual exploitation, trauma from abuse by those in authority) and combined with priority needs for adequate food, shelter, and safety, refugees are often very reluctant to engage in mental health services.

This is true for children as well and, programs that promote mental health are essential. At present the mental health service system falls short of offering the kind of comprehensive, culturally competent systems of integrated care that can effectively engage refugee youth in services. Programs that engage parents and integrate services into normative environments such as the educational system have been shown to have greater success (Ellis, Miller, Baldwin & Abdi, 2011).

## **Historical and Cultural Barriers for Non-Immigrants**

There are also many people who were born in the U.S. and who, because of cultural or historical experiences, find it difficult to engage with mental health services. While many of the factors discussed already may apply to many groups, two groups of Americans will be discussed here.

For African Americans, the history of slavery and discrimination with their attendant residuals of continuing poverty, educational systems whose funding is often related to poorer residential districts, and higher incarceration rates for young males, lead many to distrust systems, including those that provide care. These conditions, which continue in many areas to this day, can become a vicious cycle of discrimination, distrust, alienation and mainstream isolation, leading to further discrimination, distrust, alienation, and isolation – all of which may make engagement with mental health services difficult.

For Native Americans, the history of forced removal of children from their homes, imprisonment in residential schools, and the subsequent attempt to remove any traces of their culture, have left this group of Americans with considerable distrust of organized services. As with other marginalized groups, much of the stigma and discrimination remains today. Native Americans experience substantially higher rates of alcohol and drug abuse, poverty, and continued stigmatization of their cultural practices. These also can become a vicious cycle with the same features, i.e., discrimination, distrust, alienation and mainstream isolation, leading to further discrimination, distrust, alienation, and isolation. For this group as well, culture and religious beliefs may play a part in decisions about whether to engage in mental health services. The situation is made more difficult by the economic hardships faced by many Native Americans and the paucity of providers that understand and can address cultural issues that impact mental health for Native Americans (Giordano, Elliott, Sribney, Deeb-Sossa, et al., 2009).

## **Overcoming Barriers to Engagement**

Concerted action is often needed to overcome the barriers people face and work toward finding solutions that will help them engage with mental health services. For those with the most difficulties, considerable changes may be needed before people feel comfortable enough to place their trust in a system that failed them previously or that resembles a system where abuses have occurred. Individual providers and the overarching health care system will need to think outside of their normal comfort zone if we are to embrace all who need services and ensure that a welcoming and trustful environment is available. Demonstrating caring, respect and empathy, and stepping out of the traditional provider role by accompanying the person in such activities as looking for a new place to live, having a meal together, etc., are concrete ways to show that prior negative experiences do not necessarily have to predict future experiences (Farkas & Anthony, 2010).

## **Overcoming the Effects of Prior Negative Experiences with the Mental Health System and Working to Alleviate Multiple Long-Term Needs**

People with serious mental illness, especially those with multiple needs, are among the most socially excluded within any society. They can be severely functionally impaired, stigmatized and discriminated against, poor, have few friends, and be almost totally isolated (Office of the Deputy Prime Minister, 2004). Mental health systems and providers who work in them have too often blamed these individuals for their situation, labeling them as “treatment resistant” or “unmotivated”. Acceptance and understanding of the multiple problems faced by many of these individuals could go a long way toward building the trust needed to help them engage in the service delivery system. Employing stages of change models along with use of motivational interviewing (when appropriate) using trained providers could help people come to terms with their illness, the prior experiences they’ve had, the multiple issues they face, and potentially become ready to confront these challenges (Davidson, Roe, Andres-Hyman & Ridgway, 2010).

For people who have long term multiple needs, intensive assertive outreach is needed and is designed to reach out to people, establish trust, meet basic needs, and ultimately engage people in a partnership to develop a mental health services plan. Assertive outreach has the following components:

- Meeting the person on his or her own terms, including times and locations chosen by the person
- Offering a range of services, including crisis intervention
- Having an identified person available and responsible 24 hours per day
- Providing a risk management approach that offers safety for the person and the public
- Paying attention to social factors such as providing opportunities to make friends as well as to offering help with mental health and medical problems
- Providing supported access to mainstream services
- Offering support and encouragement from peers
- Offering daytime activity which offers possibilities for socialization, volunteering, and employment as desired
- Ensuring that consumers are treated as equals with respect and dignity
- Providing help with finance and benefits
- Finding suitable accommodations.

When an individual feels ready, there are several ways to facilitate engagement in services. These include encouraging greater involvement in the larger society through volunteer activities, enlisting the person’s advice about how best to help, providing paid activity, and



including the person in social activities. This can offer a sense of empowerment, address issues of poverty, establish a sense of hope, and can serve as a means to facilitate engagement, or re-engagement in the mental health service delivery system.

Due to the importance of overcoming the isolation and social exclusion that people with serious mental illnesses and in particular those with long term and multiple needs often face, considerable resources and long term commitment from the professionals involved and the systems they work for are required. Teams of professionals that cut across health and social services systems must work together to ensure people have the services they need and feel comfortable engaging in mental health treatment on their own terms and when they are ready to do so. This requires a true commitment from system leaders who must allocate resources to a) recruit appropriate staff who are willing and able to engage with people on each individual's own terms and work with people for as long as it takes, b) provide ongoing education and training for staff, and c) monitor and evaluate the range of services provided to ensure they are working and effective for the people who need them.

One way in which individuals may be helped to engage with the service delivery system is through the use of peers. Peer support personnel can be a tremendous resource for individuals who are ill. Peer support workers offer encouragement prior to contact with the system by sharing their own experiences, offering to accompany individuals to appointments, and provide support as individuals navigate through the often complex maze of services. Simply offering the support of peers does not however, negate the responsibilities that individual service providers and mental health systems have to ensure that services are accepting, person centered, genuine, and available for as long as needed. For those with multiple needs and those who are reluctant to engage in services, a comprehensive, long term approach is needed.

### **Demonstrating Sensitivity to Cultural Views and Working to Overcome Barriers**

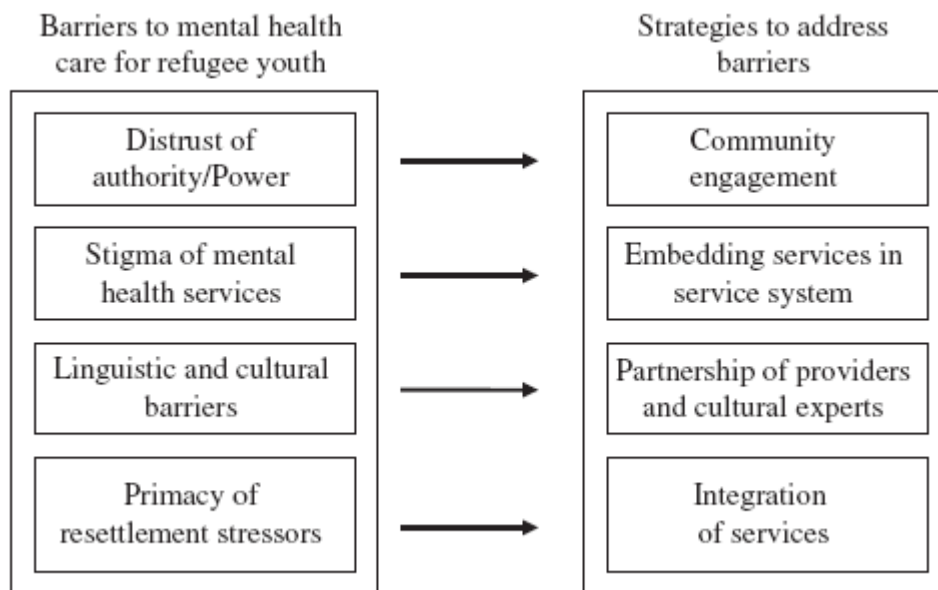
For refugees or those with cultural barriers, it is essential to recognize that family and community viewpoints will almost always have primacy over what others perceive to be mental health needs. Finding ways to engage people requires acceptance of different cultural values and beliefs, and a willingness to expend resources to move beyond such barriers. Some examples of ways to overcome barriers include hiring people that can provide translation services, providing gender specific services, ensuring that services are respectful of cultural norms and values, and offering services at times and locations convenient to the people receiving them. It may also require a willingness to include, with the person's permission, those not normally included such as clergypersons and or trusted friends. Providing education about mental illness (psychoeducation) can help to remove the stigma that accompanies serious mental illness by offering explanations that are medical rather than reinforcing stereotypes that blame the ill person. In every case, the person's cultural beliefs and values should be respected and services planned with the person in accordance with those beliefs and values. Basic needs such as having enough to eat, having

appropriate shelter, and being safe must always be met before individuals will be able to consider attending to the mental health needs of persons in their families.

For children and youth, families and their communities must be partners in developing mental health programs. Involving families and community leaders can help to diminish the fear of authority figures, lessen stigma, and develop trust. Where basic needs for safety, housing, and food have not been met, it may be necessary to arrange for the provision of these basic needs so that families can focus on ways to promote mental health rather than worrying about where they and their families will eat and sleep.

The figure below presents a graphical representation of ways to overcome these challenges. Although designed for refugee youth, the principles of engagement apply across the board.

### **Identified Barriers to Mental Health Services for Refugee Youth and Corresponding Strategies for Engagement of Cultural Communities in the Development of Services**



Source: Ellis, Miller, Baldwin & Abdi, 2011

### **Benefits of Partnering with People with Serious Mental Illness**

Although overcoming barriers faced by people with mental health disorders is important, that should not be the end of the story. A true partnership with recipients of services must be established if services are to be effective. Such partnerships can have tremendous benefits for both providers and for those who use mental health services.

No one, no matter how well trained, has the in-depth knowledge of what it is like to experience a serious mental illness, except someone who has actually experienced the illness. Unless one has experienced the onset of illness, the terrifying experiences that go with feeling separated from oneself, hearing and seeing things that others say are not present, being ridiculed for displaying strange behaviors, being forcibly treated (and often

with disrespect for one's humanity), and being rejected by friends and sometimes by family, there is no way to truly understand what it is like to have a serious mental illness. While these are experiences that we wish for no one, they are an important resource that can help to improve understanding of what people are experiencing and pave the way for better service delivery. Peers, including psychologists and other mental health professionals who have lived experience of serious mental illness and are willing to assist others in need of support, can be an invaluable resource for people as they work to become engaged with the mental health system and establish partnerships to plan for services.

Establishment of a real partnership is crucial for person centered planning and is at the heart of the recovery process. This can only be accomplished when the individual is the one who decides what goals he or she wishes to achieve, what services will best help him or her achieve the goals he or she has, and which providers would be best to facilitate the process. Clearly, this cannot happen without a true partnership. Moreover, the joint working relationship must continue throughout the entire process: going beyond goal setting and encompassing progress monitoring, evaluation of objectives and goal attainment, revising of goals where desired, and movement into other phases of service delivery as desired by the person. When fully and properly implemented, such partnerships can have real benefits for people with serious mental illness and for service providers as they witness clients' progress. Some of the potential benefits of partnering are described below. See Tait & Lester, 2005 for a more complete discussion of these concepts.

### **Minimizing the Effects of Crises**

People with serious mental illness know themselves best and can alert others to the fact that they are not feeling well. When this occurs, they can help to formulate responses that will be helpful to avert a full crisis and hospitalization. Psychologists and other mental health professionals who value and use this personal expertise can assist in averting crisis situations and reduce unnecessary hospitalizations just by listening to, and taking advice from the ill person. Wellness tools such as the Wellness Recovery Action Plan (WRAP) (Copeland, 2002) can be of great help in averting crises.

### **Determining Which Services Are Best**

People who have serious mental illness know best which services are most helpful. While providers are able to offer information about the range of services available, people with serious mental health conditions know what they need to recover and regain a satisfying life. In addition, peers are often able to suggest and help develop alternative approaches that can complement, and sometimes be more helpful than, existing services. One example of a tool designed to support recovery and encourage shared decision making is the Common Ground web application (Deegan, 2010) which combines peer support and web based technology to enhance a person's ability to make decisions related to medication use. This offers the potential for new roles for peers in the clinic where medications are discussed and use is sometimes determined. Partnering with the people who know what is

helpful can be invaluable in the redesign of mental health services to make them responsive to the needs of the people who use them, rather than the needs of the organization. The table below displays information from consumers on what helps and what hinders recovery from serious mental illness:

<b>Hinders Recovery – Programs &amp; Services</b>
Coercion & Forced Treatment
Treatment/Medication used as a means of Social Control
Debilitating Effects & Experiences of Long-Term Hospitalization
Substandard Services/ Poor Quality Assurance
Limited Access to Services & Supports/ Timeliness, Time limits
Fragmentation of Services, Eligibility Restrictions
Lack of Individualization
Lack of Needed Range of Services, Treatments and Options
Lack of Education for Consumers, Family Members and Community (e.g., illness, self-care, services, etc.)
Inadequate Continuity of Care

<b>Helps Recovery- Programs &amp; Services</b>
Forced Treatment Avoided
Freedom of Whether & How to Participate in Services & Meds/ Self-Management of Medications
Inpatient Services as Last Resort but Available/ Small Scale/ Alternatives to Hospitalization/ Self-Directed Inpatient Care/ Advanced Directives Respected
Quality Clinical Care/Consumer-Doctor Partnership/Up-to-date Treatment Knowledge /Clean & Modern Program Environment
No Waits/ Flexible
Coordinated Services Across Problems, Settings, & Systems/Effective Case Managers with Low Caseloads & High Pay/ Disengagement or Reductions in Services Based on Consumer’s Self-Defined Need
Tailored to Individual/ Wide Range of Choices as to Who Provides, What is Provided & Where Provided
Peer Support Services/ Therapy & Counseling/Atypical Meds/Family Services/Employment Support & Career Development/Respite Care/Integrated Dual Diagnosis Services/Jail Diversion and Community Reintegration Services
Patient Education/ Illness Education/Information on Meds, Effective Treatments & Services & How to Secure, Rights/ Family Education/Public Awareness Education (anti-stigma & pro-recovery)
System Navigators/ Extensive Out-reach & Support (multiple languages, 24-7, minority-focused)/ Homeless Outreach/ Safety Net Services
Access to Records/ Can Change Inaccurate Information
Early Intervention & Public Screenings/ Outreach to Churches, Schools, Community

*Onken, Durmont, Ridgway, Dornan & Ralph, 2002.*

### **Potential Therapeutic Benefits**

For individuals with serious mental illness, being a true partner and actively involved in the system may be therapeutic in and of itself. Taking an active role and being valued for one’s input and expertise can be immensely empowering. For this to be true, the partnership must be real, i.e., not superficial, and one where individuals are actively sought out for their expertise and where their advice is followed.

## **Research Participation**

Research involvement is another area where important contributions can be made. The priorities of people with mental health disorders are often different from those of service providers and university researchers who may be responding to requirements from funding organizations. Peers are often the best ones to interview other consumers because they are likely to be seen as more credible and trustworthy than professionals or graduate students. Responses may be more accurate or more detailed when a trusting relationship exists, especially if the research subject and the interviewer have similar cultural or experiential backgrounds. It is important for persons with lived experience to be active in all phases of the research project because they are more likely to identify important questions or hypotheses that may have been overlooked, identify points where subjects are likely to feel uncomfortable and become unresponsive, and suggest better analytic tools that can enrich and explain findings.

## **Staff Selection and Training**

Service users are often in the best position to help select providers and suggest the kinds of training needed to provide the array of services needed. Despite the need for adequate professional qualifications, individuals with mental health disorders are often more sensitive to the personal characteristics of applicants such as one's ability to connect with another and develop an empathic relationship – those very characteristics that have been shown to be the best predictors of successful outcomes (Anthony, Cohen, Farkas & Gagne, 2002; Kirsh & Tate, 2006). People with serious mental illness can be very helpful in challenging the many myths about severe mental health disorders and in getting providers to understand what it is like to be on the receiving end of services. This could be one of the most important benefits of partnering with people with lived experience and may be one of the first steps in moving toward a recovery oriented system of care.

## **Challenges**

For many people with serious mental illness, it is difficult to engage in the service system. For some, the services they want or need may not be available. For others, there may be resource issues such as lack of transportation or lack of child care. For still others, there may be cultural reasons why receiving mental health services is difficult. For other people, there may be trauma associated with prior mental health experiences. For many, there are more basic unmet needs that make attending to one's mental health the last priority.

Many of these challenges are systems level issues that psychologists and other providers must acknowledge and work to remedy. As discussed in the Community Inclusion module, psychologists have an ethical responsibility to work to achieve the best interests of the people they serve. And, as discussed in the module on person centered planning, individuals with serious mental illness must be the guiding force behind their service plans. This is hardly possible unless the system has taken steps to overcome barriers it has placed

in the way, and providers are truly committed to the recovery philosophy and working to remove these barriers. Despite our knowledge of the need for engagement and the benefits of partnering with people with serious mental illnesses, few systems have invested the resources needed to help people overcome the barriers they face. And, partnering with people with serious mental illness cannot be a discrete program – it must be part of every aspect of the mental health service system. Encouraging mental health systems to expend the resources necessary to break down the barriers that keep engagement and partnership from happening can be quite a challenge, especially when resources are scarce. Resources are not the only issue however. Much can be accomplished by treating people with respect and by demonstrating genuine acceptance of each person’s unique situation and preferences.

With respect to psychologists and other providers, most have not been trained to attend to the multitude of barriers people with these illnesses often face. Nor have they been exposed to or trained in methods to help people find ways to overcome these barriers. In most every mental health system and in most training programs, we continue to consider people with serious mental illness who have difficulty engaging as treatment resistant, unmotivated, uncooperative, unwilling to help themselves, and undeserving of the resource expenditures (both personal and system wide) it could take to help them engage and become true partners.

This is quite a loss both for those with serious mental illness and for providers who have at least as much to gain from such partnerships. It is only after working on an equal level with people with severe illness that one realizes how little insight most professionals actually have and how much we have to learn. This can be highly threatening for providers who may find it difficult to see those with serious illnesses as experts and let go of the idea that we are those who know best.

For challenges posed by cultural factors, systems level and provider commitments are also required. Mental health systems must be committed to hiring adequate numbers of providers with similar cultural backgrounds and with appropriate training in trauma services. Mental health systems must be prepared to work closely with community leaders and organizations to offer programs and services when, where, and under conditions that are acceptable to people from specific cultural backgrounds. Religious and social conventions must be respected. Systems and providers must be willing to stay the course to establish trust – an endeavor that can take time, particularly when one considers that many immigrants, and refugees in particular, have great distrust for anyone in authority.

Overcoming the challenges faced by people with serious mental illness is not easy, either for those affected, their families, the systems designed to help them, or for psychologists and other providers. Given the tremendous need for services by those who face these often overwhelming obstacles that are in addition to their illness, every attempt to achieve success in engaging and partnering with people must be seen as worth the effort.

## Summary

The mental health system in North America has not performed well in terms of reaching out to those who need services, engaging them in the system and partnering with them to design the services they desire and need. As a result, most people who need mental health services do not receive them. This is especially true for people who arrive as refugees. It has been estimated that the vast majority of refugees who need mental health services never receive them.

The reasons why people do not receive mental health services are varied. Some of those reasons are accounted for by financial and other resource barriers, some are accounted for by prior experiences that make the thought of accessing mental health services distasteful, some reasons are accounted for by the multiple needs that many people with serious mental illnesses face, and some reasons involve cultural factors that substantially limit the person's ability to access or accept services. Often mental health systems and providers themselves are not welcoming to people with serious mental illness and blame them for the problems they face. This further alienates people who are already isolated and afraid of the system and those in authority.

Engaging people in a partnership with mental health services is an essential component of the recovery paradigm. Psychologists have an ethical responsibility to advocate for changes to service delivery systems, to training programs, and to their own belief systems in order to overcome the barriers and challenges that make access, engagement, and partnership difficult for many people.

Engaging people with serious mental illnesses and partnering with them has many benefits. In addition to the obvious benefits of engaging people in their service plan and its implementation, there are many potential benefits for systems and for providers when people with serious mental illness are true partners. These include:

- Potential to minimize the effect of crises
- Potential to learn directly about the illnesses and needs for services
- Potential therapeutic benefits
- Advantages of having people with lived experience involved in prioritizing and conducting research
- Benefits for involvement in staff selection and training

Despite these benefits, the challenges many people face are substantial. Mental health systems, psychologists, and other providers must be willing to dedicate the resources needed to help people overcome these challenges so they can become active participants in the systems designed to serve them.

## Sample Learning Activity

There are two parts to this activity. For the first part of this activity, the group should be broken into small groups of about four participants. In each group:

One person should assume the role of a person with serious mental illness who has had very negative prior experiences with the mental health system;

A second person should assume the role of someone with serious mental illness who has multiple needs;

A third person should assume the role of someone with serious mental illness from a cultural background that either does not acknowledge the existence of mental illness or does not accept treatment especially for a young person or for women;

The fourth person should assume the role of psychologist provider and recorder.

The three participants with serious mental illness should each describe his or her reasons for being reluctant to take part in mental health services. The psychologist recorder should write down the reasons each person gives so they can be shared with the larger group.

For the second part of the activity, the smaller groups should come back together to re-form the larger group.

Each psychologist recorder should read the reasons for not wanting to engage with the mental health system for his or group related to one of the categories, i.e., person with prior experience, person with multiple needs, or person with cultural barriers. All of the reasons for each category should be read for that category from all of the small groups. The psychologist recorders should then elicit responses from the group about how they would respond to each reason, across all the small groups, and the psychologist recorders should record these.

Proposed responses could include verbal responses or actions they might take. Those who portrayed people with serious mental illness should indicate if the proposed ways of responding would really make a difference in helping them to engage with mental health services, and if not, what would have been helpful.

After the first category has been completed, the same exercise is repeated for the second category, and for the third. The leader should ensure that there is enough time to respond to all three categories.



## Sample Evaluation Questions

<u>Question</u>	<u>True</u>	<u>False</u>
1. The goal of self-direction is more important than a person's cultural preferences		X
2. Most of the reasons people with serious mental illness are reluctant to take part in mental health services have to do with their internal experiences		X
3. In order to help people engage in services, professionals must be empathic and experts in various forms of psychotherapy		X
4. Assertive outreach includes ensuring the persons to be served have their basic needs met, including those for safety, shelter, and suitable activities	X	
5. Some of the most important benefits psychologists and other providers can gain from working alongside people with serious mental illnesses as equal partners include expanded insight into research, staff selection and training, and learning about the true benefits of various services that people experience		X

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## **Additional Resources**

American Psychological Association Recovery to Practice Initiative.

<http://www.apa.org/pi/rtp>

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## Citing the Curriculum

Citation for this Module:

American Psychological Association & Jansen, M. A. (2014). Engaging People as Partners in the Design, Delivery, and Evaluation of their Mental Health Services. *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

Citation for the full Curriculum:

American Psychological Association & Jansen, M. A. (2014). *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

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# American Psychological Association

## Recovery to Practice Initiative Curriculum: Reframing Psychology for the Emerging Health Care Environment

### *5. Person Centered Planning*

August 2014

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## Overview

In this module of the course we will discuss the concepts and methods involved in person centered planning.

## Learning Objectives

At the end of this module you will be able to:

- Discuss at least four concepts of person centered planning and its relation to the recovery philosophy
- Identify and describe at least five cultural factors that must be taken into account in any planning and service delivery enterprise
- Describe at least three barriers to implementing person centered planning and discuss the reasons why these must be overcome prior to implementing the process
- Identify the five steps that make up the person centered process and discuss the essential components of each
- Describe at least three practices to facilitate true person centered planning

## Resources

- Lecture Notes
- Required Readings
- Lecture Notes Citations
- Sample Learning Activity
- Sample Evaluation Questions
- Additional Resources

## Required Readings

Adams, N. & Grieder, D. M. (2005). *Treatment Planning for Person-Centered Care*. Burlington, MA: Elsevier Publishers.

Davidson, L., Rowe, M., Tondora, J., O'Connell, M. & Staeheli Lawless, M. (2008). *A Practical Guide to Recovery-Oriented Practice: Tools for Transforming Mental Health Care*. Chapters 1 and 2. Kettering, Northamptonshire, UK: Oxford University Press.

Tondora, J., Pocklington, S., Osher, D. & Davidson, L. (2005). *Implementation of Person-centered Care and Planning: From Policy to Practice to Evaluation*. Washington DC: Substance Abuse and Mental Health Services Administration.

## Activities

Complete the following activities:

- Read the lecture notes
- Read the required readings
- Engage in a learning activity related to this module
- Evaluate students' understanding of this module.

## Lecture Notes

People with lived experience of serious mental illness are strongly encouraged to be part of the delivery of the curriculum including being active participants in the delivery of the lecture. Refer to the curriculum Instruction module for additional information.

### Introduction

The concept and process of person centered planning are integral to the philosophy of recovery and essential for a mental health system to be truly a recovery oriented system of care. Person centered planning embodies the recovery movement as it places the individual with serious mental illness at the heart of everything that is undertaken to facilitate the person's recovery. The right to make choices for oneself is a fundamental human right that is not contingent on freedom from symptoms. Every person has the right to be involved in, and make decisions about services received, how and where to live, with whom to associate, etc. Person centered planning is the operationalization of respect for a person's right to make these choices.

Recent research has demonstrated the value of person centered planning for people who receive services (Holburn, Jacobson, Schwartz, et al., 2004; Robertson, Emerson, Hatton, Elliott, et al., 2005; 2007; Sanderson, Thompson & Kilbane, 2006), and it has been found that person centered planning does not lead to a significant increase in costs (Robertson, Emerson, Hatton, Elliott, et al., 2007).

As we will see later in this module carrying out person centered planning is not easy to do. There are many barriers and it is much more difficult to actually carry out this work than might be imagined because, like other aspects of the recovery paradigm, doing so requires a shift in thinking and a departure from the way that most were trained.

So, what exactly is person centered planning? At its most rudimentary, person centered planning means that the person with the illness is the fulcrum around which all discussions, planning, interventions, evaluations, etc., occur, and it means that the person is in charge of defining future directions for his or her life. This means that nothing is planned or undertaken without the person's active input and approval. As will be seen, the steps in the process require much more than simply having the person present or asking the person to agree with, or "sign off" on assessments, goals, interventions, and evaluations. All of these must emanate from the person him or herself. This may be easier said than done, especially when done correctly. Another important aspect is that person centered planning often requires that community agencies be involved in order to ensure that the person is fully integrated into his or her community. As such, the process differs considerably from traditional service planning approaches where each agency typically provides only those services within its mandate and does not concern itself with service deficits outside its own mandate. The table below provides a graphical depiction of the

differences between traditional approaches to planning and service delivery and one that is person centered, sometimes referred to as personal strategic planning.

### Traditional versus Person Directed Approach

Traditional Approaches	Person-Directed
Self-determination comes <i>after</i> individuals have successfully used treatment and achieved clinical stability	Self-determination and community inclusion are fundamental human rights of all people
Compliance is valued	Active participation and empowerment is vital
Only professionals have access to information (e.g., plans, assessments, records, etc.)	All parties have full access to the same information – often referred to as “transparency”
Disabilities and deficits drive treatment; Focus is on illness	Abilities/choices define supports; Wellness/health focus
Low expectations	High expectations
Clinical stability or managing illness	Quality of life and promotion of recovery
Linear progress and movement through an established continuum of services	Person’s chooses from a flexible array of supports and/or creates new support options with team
Professional services only	Diverse supports (professional services, non-traditional services, and natural supports)
Facility-based settings and professional supporters	Integrated settings and natural supporters are also valued
Avoidance of risk; protection of person and community	Responsible risk-taking and growth

Source: Tondora, 2011

## Historical Origins

The concept of person centered planning originated in the developmental disabilities field and came about in the 1960s because of the recognition that planning for, and delivery of services should include individuals themselves and their families, and should be built on the strengths of the individual and the goals he or she has for his or her life. Disability rights advocates argued for inclusion of individuals and their families in the planning and service delivery process and argued that people with disabilities should be considered full members of their community and the larger society. It was at this time that the Principle of

Normalization was developed (Nirje, 1969; Wolfensberger, 1972). The Normalization Principle espouses the belief that all people should have access to the rights, roles, and responsibilities that are part of everyday life and that those with any disability or impairment should be treated with respect, provided functional supports only as they need and want them, and treated in the same way that people without a disability or impairment are treated. This would include making informed decisions and the idea was quite discordant with the way people with disabilities were viewed and ultimately paved the way for many of the changes that came about in later years.

Following this, the Self Determination movement was initiated. The Self Determination movement espoused the notion that professionals alone should not determine the services received, but rather that individuals should be involved in all decisions related to medications and the services they would receive. The Self Determination movement also proposed that individuals should be fully integrated into the community in which they live (O'Brien, 1989).

Following these initial efforts, several others began outlining the concepts and processes involved in a system that recognizes the importance of putting the person at the middle of the planning and service delivery process. In the mental health field, these developments led to the evolution of the recovery movement where persons with serious mental illness and some professionals recognized that recovery and living a satisfying life in the community are possible. The person centered planning process is now central to provision of services that are recovery oriented.

## **The Importance of Culture in Planning and Service Delivery**

Prior to beginning a discussion about the process and steps involved in person centered planning, a discussion about the importance of cultural factors is in order. The influence of a person's culture, background, religious beliefs, and or upbringing are important considerations that are often overlooked. This is becoming more evident as the population becomes increasingly heterogeneous. Cultural factors, including religion, beliefs about mental illness, its etiology, and its acceptability, views regarding a person's right to make choices as opposed to having those choices made for him or herself, to name just a few, can substantially impact on the planning process, services received, and recovery process. Language barriers can also have a profound effect on ability to communicate the many important facets of a person's life and background – all these impact on the planning process. A few examples follow.

In some cultures, the concept of mental illness is virtually non-existent as behaviors are considered to be under the control of spirits or other forces that can be controlled by indigenous healers or faith based providers (Constantine, Myers, Kindaichi & Moore, 2004; Malarney, 2002). Another factor is that in many cultures, mental illness and attendant behaviors are highly stigmatized making help seeking extremely difficult if not impossible.

There are also many cultures in which young people do not ordinarily make decisions or choices for themselves but defer to the wishes of their elders (Ellis, Lincoln, Charney, Ford-Paz, et al., 2010; McKay, Hibbert, Hoagwood, Rodriguez, et al., 2004). Similarly, some cultures do not afford women the opportunity to express opinions or make decisions, reserving these for male members of the family (Said-Foqahaa, 2011). In such cultures, it could be very difficult for the person with the illness to participate actively in the planning process and take part in determining the future direction for his or her life. This may be especially important if talking about sexual health issues is not permitted. Issues such as sexually transmitted diseases and contraception have the potential to impact on physical well being and one's future life, making these important to discuss.

Another cultural issue that is not often discussed involves trauma resulting from family perpetrated physical or sexual abuse. Although this occurs in some cultures, it is not officially sanctioned. However, in some cultures women and sometimes children are seen as property to be used as desired (Chaudhuri, 2005; Said-Foqahaa, 2011), and these practices may be overlooked or unofficially sanctioned. This is rarely discussed but leads to tremendous trauma for the victim and sometimes for the perpetrator as well.

Although the above examples may appear to be irrelevant to many, there are remnants of the same beliefs and practices in the U.S. There are also many recent immigrants from societies where the above examples are prevalent. Sensitivity to individuals from backgrounds that differ from what might be considered the mainstream is essential if steps toward person centered planning and services are to be taken. In such cases, greater attention to family beliefs and preferences should be considered primary while attempting to involve the individual to the greatest extent possible and facilitate planning, service delivery, and ultimately recovery on the person's and family's terms. In all cases, the person's wishes about culturally influenced choices must be respected.

## **The Process and Steps Involved in Person Centered Planning**

Prior to beginning the discussion of the steps involved, two important components should have occurred or be in place. First, the individual him or herself should want to receive services from the mental health system and should have asked for assistance. Secondly, the mental health system should be one that actively promotes and supports a recovery orientation and person centered planning. Without such commitment, mental health practitioners will find it difficult to undertake person centered planning and to follow through with agreements made with the people receiving services (Walker, Koroloff, Schutte & Bruns, 2004).

The definition below of a patient centered intervention indicates very concisely what is involved in developing a set of interventions that are truly person centered:

**A patient-centered intervention for people with serious mental illnesses is defined as:**

An organized process of care or service delivery that is directed by the person receiving services. Care and services are delivered collaboratively, attentively, and compassionately, with providers as partners who understand and respond to the person's perspectives, culture, and concerns. The delivery process is structured to educate, inform, guide, and assist the person to be a knowledgeable consumer of the services relevant to attaining the person's self-defined needs, goals, and outcomes, taking into account the person's individual circumstances.

All individuals, including those who have been diagnosed with a serious mental illness, have the right to direct their own care. People who are limited in their ability to direct their care as a result of acute symptoms or legal constraints should be provided with the support necessary to make as many care-direction decisions as possible. If a person is unable to make informed choices about his/her care, providers will rely on historically expressed preferences and values and, when available, psychiatric advance directives and designated surrogates to maximize the person's participation in decision-making about services and treatment. Care decisions made for persons when they are unable to direct their own care should be based on the premise that such decisions will enable those persons to make future choices about their care. Care and services provided to service users should take into account available scientific knowledge and the resources of the service system.

*Definition of a patient-centered care and service delivery intervention. From: Green, Estroff, Yarborough, Spofford, Solloway, Kitson & Perrin, 2014.*

Psychologists are especially well trained to work with individuals from a person centered and recovery perspective because of the training and emphasis on strengths and helping individuals overcome diversity to lead fulfilling lives. Psychological interventions such as CBT and the strengths based approaches of Positive Psychology are two examples of the unique intervention modalities that are to be called upon in all phases of the person centered approach to working with individuals with serious mental illnesses.

### **Initial Meeting**

During the initial meeting, the approach of person centered planning would be discussed with the individual and he or she would be asked to think about, and for future meetings, to involve as many individuals that he or she trusts and wants to ask to be part of the process. The identified individual(s) should be asked to take part in the process with the person, not to speak for him or her, but to provide support and fill in detail, as requested.

Following the initial meeting, one or more additional meetings will be necessary to carry out an assessment, design a plan that will assist the person to achieve the goals she or he sets, evaluate progress, and potentially develop additional or revised goals, and make transition plans.

### **Assessment**

For psychologists, an assessment carried out as part of a person centered planning process is very different than one that would be undertaken for diagnostic or other clinical reasons. Clinical assessments are typically done to label someone's illness, usually because some part of the system requires such a label. Reasons for requiring a diagnostic label could include insurance reimbursement requirements, a medically oriented system where

practitioners feel more comfortable if the illness has a diagnostic category, judicial review requirements, etc. An assessment that is undertaken as part of person centered planning is done to find out what the individual wishes to achieve and to identify the assets available and challenges to be overcome in order for the person to reach the goal(s). A person centered assessment is one in which the person identifies his or her goals, strengths, and challenges, in as much detail as possible, and conveys these to the service provider. Strengths and challenges are not limited to those intrinsic to the person but include those available or desirable in the person's support system and wider community.

Prior to beginning the formal assessment process, it is important to explore with the person his or her interest in the planning process. All too often, service plans are written assuming that individuals are ready to take action, when people may not actually be ready to do this. The result can be that the person does not participate in the planning process and the person is labeled non-compliant or resistant. In order to avoid this, exploring with the individual thoughts about his or her readiness for the process, and reaching out to the person with a focus on engagement and building trust, would be the first course of action (Adams & Grieder, 2005; Osher, Osher & Blau, 2005).

Once the person is ready to begin, the assessment process can begin. Some components of a person centered assessment include – each identified by the individual and explored in detail:

- Personal strengths viewed as an important personal asset
- Areas for improvement:
  - Employment – what kind
  - Education – in what areas
  - Socialization – what kind, how frequently, with whom
  - Leisure – what kind, how frequently including interests not explored
- Community/environmental resources and assets that can be accessed
- Problems/issues:
  - Financial, legal, safety, medical, interpersonal relationships
- Living situation:
  - Preferred, realized, including location and with whom
- Mental health:
  - Current status, i.e., doing ok, receiving services, having problems, etc.
- Issues not identified or discussed such as trauma, abuse, medication, etc.
- Desired outcome of services – where would the person like the process to end up?



Once all components of the assessment have been completed and reviewed, an integrated summary should be written that pulls together all of the information into an integrated whole that paints a coherent picture of the person and his or her world. All aspects of the assessment and summary are shared with the person and others according to the person's wishes. The Assessment module of this curriculum contains greater detail about conducting a strengths based assessment.

## **Creating the Plan**

Once the assessment and integrated summary are completed and all are agreed that these present a comprehensive vision of the person's strengths, challenges, and overall goals, a plan for building on those strengths, making strides to overcome the challenges, and work toward goals can be developed.

As with the assessment and summary, the plan should be developed together with the individual and any others that he or she wishes to involve, and all should receive copies of it.

The plan will have three overarching components: goal(s), objectives, and interventions. Each of these is discussed below.

### *Goal(s)*

The goal or goals are accomplishments that the individual wishes to achieve. They can be long term as the person may have some goals that will take a while to achieve, but ideally goals should be ones that can be accomplished within a year. Additional goals can be added as the person achieves earlier ones, or as the person determines that initial goals should no longer be included. Goals can be written fairly broadly such as return to school, live independently, etc. Goals should build on the person's strengths and be written with the person's culture and values in mind. The number of goals should be manageable and realistic so that to the greatest extent possible, they can be accomplished. However, practitioners must be careful that their own view of what is realistic does not supersede the wishes of the person. Goals that are truly unrealistic such as "I want to be the first person to land on the moon", can be listed and discussed openly and non-judgmentally without imposing the provider's will on the person. All goals that the person expresses should be considered and discussed in a non-judgmental perspective.

### *Objectives*

Objectives can be seen as the steps needed to reach each particular goal. Objectives should be based on the strengths and abilities of the person and usually involve the steps needed to overcome a challenge or barrier that was identified during the assessment or that is identified as the process moves forward. Objectives are developed with and by the person and should be achievable and realistic in that person's eyes. A helpful mnemonic that has been adopted for use in person centered planning (Tondora, 2011) and that can be used to prompt the writing of good objectives is that objectives should be SMART:

- Specific
- Measurable
- Attainable
- Realistic
- Time-bound (Doran, 1981).

### *Interventions*

Interventions can be thought of as assists that will be provided to help an individual as he or she works through the objectives on his or her way toward one or more goals. Like objectives, interventions should also be written in specific terms identifying what the intervention will consist of, who will provide it, how often it will be provided and for how long it will be provided. While interventions are often thought of as the purview of professionals, they may also be activities that are carried out by family members, supporting individuals, or from resources available in the community.

Strength-based approaches are not limited to adults and are ideal for children and young people as well. Interventions that draw on strengths should be implemented across the age span at the individual child and family team level, with adults, and with older adults at both the individual level and at the community level as well (McCammon, 2012).

Competency-building and promoting mental wellness are complementary approaches that should be used in conjunction with treatment interventions (Miles, Espiritu, Horen, Sebian & Waetzig, 2010). As with objectives, the plan should provide specific information about interventions, including:

- What the intervention consists of
- How frequently it will be provided
- Its duration, or for how long it will be continued
- Who will provide the intervention
- Its intended impact (Tondora, 2011)

### **Evaluating Progress and Making Revisions as Needed**

Reviewing progress and updating the plan on a regular basis is important to ensure that it remains focused on helping the person achieve his or her recovery goals. Reviews should take place when milestones are achieved or when problems arise that may interfere with progress. Otherwise, quarterly reviews provide a good opportunity to “check in” to see how things are moving along. Progress reviews can be a good time for assessing what has gone well, what has become a stumbling block, and what has been learned about all aspects of the plan and about the participants in the process. It should never be considered that failures have occurred; rather evaluating progress should be seen as a learning opportunity for personal growth.

During the review process, the person can describe progress, thoughts about the plan, and discuss his or her satisfaction with its components, and those involved in helping with it and providing interventions. Any adjustments that need to be made to any aspect of the plan can be made during the review meeting.

It is important to note that goals may not always be achieved. There are many reasons why a goal might not be reached and these can range from simple ones such as it was no longer important to the person, or the resources needed to reach the goal are no longer available. The planning team, led by the person served, can evaluate what has impeded accomplishment of the goal and the plan can be re-written to focus on something that may now be more important or more attainable. Plan changes should not be seen as failures – all of us encounter setbacks that require changes to even the best plans. Alterations should be viewed as learning opportunities where all can benefit from the knowledge gained about new or continuing strengths and challenges, both at the person or provider level and at the system or community level.

### **Making Transitions**

There are several points when transitions will occur and planning for these is important. Some of these include times when the person is satisfied that goals have been achieved, requested services have been received, the person indicates a readiness to move on, or other life changes require transitioning to a different planning process with the person. If the person is to remain connected to the service system, a new planning process may need to be initiated for the next phase of services. Planning can occur as often as the person wishes; it does not need to be an annual event or occur only when transitions are on the horizon.

### **Challenges**

Person centered planning means working in a truly participatory environment by ensuring that the person is the driving force in every aspect of the process, building on the person's strengths and capabilities, and continually revisiting the plan and its outcomes with the entire team. While the concept seems simple enough, there are many challenges or barriers to true implementation of such a process.

One potential barrier that should be explored at the very beginning is working with the person to determine that he or she is truly ready to begin the process. If not, it may be necessary to reach out to the individual to engage him or her in the recovery process. Even small steps that the person chooses to work on can go a long way toward averting failures due to the provider's enthusiasm to get the process off the ground, when the person may not be ready to do so.

Another important challenge is that most mental health systems and the practitioners who work in them, have considerable difficulty dispensing with the traditional view of persons requesting services as people to be directed to whatever the provider deems best. In all cases, the individual must be the driving force who directs the process.

System administrators and practitioners (like most everyone) find changing the way things are done to be anxiety provoking and often very difficult to deal with. Excuses for resisting change range from the perception that costs will increase due to the need to train staff and create new infrastructures, to beliefs that consumers are not capable of real participation or will be dissatisfied with the services they receive.

Another challenge is ensuring that person centered planning is implemented properly. There may be poor or partial implementation attempts leading to less than desired results with the concept of person centered planning taking the blame for the failed attempt. Peer specialists can play a vital and cost effective role here.

Like the recovery process itself, of which person centered planning is a part, undertaking a participatory process with the people receiving services requires a paradigm shift on the part of decision makers and practitioners alike. This can be challenging to accomplish.

## Summary

Person centered planning is a collaborative and interdisciplinary process and is an essential component of the recovery paradigm because at it's most basic level, it means that the individual is the decision maker for all aspects of the process from the point of requesting services, to choosing helpful family or friends to participate, to working through the assessment process, to deciding upon goals, objectives, and interventions to meet the goals and objectives, and to evaluating progress and satisfaction throughout the entire process.

Although it may sound quite simplistic, implementing person centered planning requires a dramatic shift in thinking both on the part of service delivery systems and professionals in those systems because it puts the individual to be served in the driver's seat and equalizes the level and status of the system and its professionals. This is quite a radical departure from the way most systems are organized and the way most professionals are trained to think about themselves and the people they work with.

Person centered planning cannot be carried out by one or two professionals within a system. The organization must be committed to the process and to following through with commitments made with the people who will be the recipients of services. This requires a true paradigm shift. The full process involves several steps beginning with a request for services from the individual, to assessment, goal(s) identification, defining objectives to meet the goal(s), deciding upon interventions to overcome any challenges that might hinder meeting the objectives, evaluation of the process and interventions, revising the plan as needed, and transition planning. All steps and points in the process require the involvement of the person, who is the reason for undertaking the work and is at the heart of the process.

## Sample Learning Activity

First, explain to the group that this exercise will be an opportunity to look more closely at issues and policies that affect the lives of people with serious mental illnesses. The purpose of the exercise is to discuss the ways that people with serious mental illnesses are affected by stigma and decisions that are made for them instead of with them. This includes policies that service systems have about who makes decisions – typically the service provider. System policies have profound impacts on: access to health care, child care, employment, vulnerability to violence and abuse, abuse from law enforcement, to name just a few.

With the group, generate a list of topics that the group would like to address and have the group choose their top 3 – 4 topics. Example of topics that can be considered include (different/additional topics can be used):

Health Care – access and decision making

Education – decisions are made about who can access higher education

Work – in paid or volunteer employment

Housing – decisions are made about who can live in what kind of housing

Divide the large group into 3 – 4 small groups; each small group will consider one of the topics decided by the large group. Participants can choose which group they join.

Distribute the small group discussion questions below and review the questions with the large group. The small group discussion questions are:

1. When planning for services, how do policies made by the service system affect people with serious mental illnesses and how can person centered planning help to overcome the negative impact on people's lives?
2. What is the impact of this issue on your community?
3. What are some ways that mental health service providers and those affected by serious mental illnesses can address this issue?

Small groups then discuss the questions and prepare a presentation for the large group. If the group doesn't know the answers to a question, don't guess. Instead, think about what additional information could help to answer the questions. One person from each small group is designated as the rapporteur. When finished, the rapporteur will present the small group's discussion to the large group. Only one answer to each question will be presented.

Reconvene the large group and have each small group present their discussion by presenting one answer to each question. If time permits, the large group can discuss. The main point of this exercise is to expose participants to using a serious mental illness perspective and to see how that perspective can influence our approach to clinical services, including ways to change policies and practices that discourage people most affected from making decisions about their goals and services that will help them achieve those goals.

## Sample Evaluation Questions

<u>Question</u>	<u>True</u>	<u>False</u>
1. A diagnosis is essential to understanding the person with serious mental illness and is a crucial first step in the assessment process		X
2. The individual with serious mental illness should be present at any meeting where he or she is discussed and the person should receive a copy of any documents that are prepared relative to him or her	X	
3. A discussion of strengths should be a central focus of every assessment, plan, evaluation process, and summary prepared	X	
4. Person-directed planning means the person should make his/her own decisions without input from people who are natural supports to the individual, such as family members and/or trusted friends		X
5. A goal of person-centered planning is to encourage and work toward greater community inclusion for people with serious mental illnesses	X	

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## Additional Resources

- American Psychological Association Recovery to Practice Initiative.  
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## Citing the Curriculum

Citation for this Module:

American Psychological Association & Jansen, M. A. (2014). Person Centered Planning. *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

Citation for the full Curriculum:

American Psychological Association & Jansen, M. A. (2014). *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

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# American Psychological Association

## Recovery to Practice Initiative Curriculum: Reframing Psychology for the Emerging Health Care Environment

### *6. Health Disparities*

August 2014

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## Overview

This module presents information about the disparities in health care for people with serious mental illnesses compared to people with physical illnesses and also presents a review of some of the mediating factors that impact on these disparities. In addition to disparities between physical and mental health care, there are also disparities for racial and ethnic minority individuals with serious mental illnesses compared to non minority individuals with similar illnesses. These factors and the implications for treatment are discussed.

## Learning Objectives

At the end of this module you will be able to:

- Discuss at least two differences in mortality observed for people with serious mental illnesses compared to people who do not have serious mental illness
- Identify and discuss at least three factors that contribute to the disparities in mortality for people with serious mental illnesses
- Identify at least three reasons that make lifestyle changes so difficult for this population
- Discuss at least three disparities in mental health treatment for people of racial and ethnic minority backgrounds compared to non minority individuals

## Resources

- Lecture Notes
- Required Readings
- Lecture Notes Citations
- Sample Learning Activity
- Sample Evaluation Questions
- Additional Resources

## Required Readings

Lawrence, D. & Kisely, S. (2010). Inequalities in healthcare provision for people with severe mental illness. *Journal of Psychopharmacology*, 24, 4 (supplement), 61–68.

Parks, J., Svendsen, D., Singer, P. & Foti, M. E. (Eds.). (2006). *Morbidity and Mortality in People with Serious Mental Illnesses Technical Report 13*. Alexandria, VA: National Association of State Mental Health Program Directors Council.

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## Activities

Complete the following activities:

- Read the lecture notes
- Read the required readings
- Engage in a learning activity related to this module
- Evaluate students' understanding of this module.

## Lecture Notes

People with lived experience of serious mental illness are strongly encouraged to be part of the delivery of the curriculum including being active participants in the delivery of the lecture. Refer to the curriculum Instruction module for additional information.

### Introduction

People with serious mental illnesses often receive less attention for both mental and physical illnesses in the health care system than people who do not have mental health disorders. There are also disparities in health care provision for individuals from racial and ethnic minorities with serious mental illnesses compared to non minority individuals with similar illnesses. Both of these disparities are mediated by the seriousness of the mental illness, the socioeconomic status of the individual, and whether or not the individual has a family or other support system to advocate for appropriate and timely health service provision. These disparities are evident when comparing morbidity and mortality related to mental illnesses versus physical illnesses, and when reviewing evidence related to services provided to racial and ethnic minority groups versus services provided to Caucasians.

Although these disparities were known by many for quite some time, the U.S. Surgeon General's Report (U.S. Department of Health and Human Services, 1999) documented the differences in morbidity and mortality between people with physical and mental health disorders. The Report spawned a dramatic increase in funding for, and publication of research on these and related differences in health care access, utilization, and outcomes.

In addition to the differences between outcomes for people with physical and mental illnesses being complicated by factors such as race, ethnicity, culture, socioeconomic status, and gender, the interactions between and among these are complex and not always consistent. This module provides information about the disparities in health care that exist for people who have physical and mental illnesses, and considers the disparities in health care that exist for members of racial and ethnic minority groups, those from lower socioeconomic groups, and gender differences in health care provision.

### Disparities in Provision of Health Care for People with Physical and Mental Illnesses

In 1999, the U.S. Surgeon General released the first report dealing with mental illnesses (U.S. Department of Health and Human Services, 1999). The Report noted that one in four Americans had a mental disorder and that two thirds of those did not receive treatment for their illness. The proportion of people with mental health disorders is highly similar throughout the world and similarly, most do not receive treatment (World Health Organization, 2001).

In the U.S., individuals with serious mental illnesses are now known to die an average of twenty five years earlier than those without these illnesses (Colton & Manderscheid, 2006; National Health Policy Forum, 2009; Parks, Svendsen, Singer & Foti, 2006; Roshanaei-Moghaddam & Katon, 2009; Schroeder & Morris, 2010). These deaths occur as a result of both natural causes such as cancer, cardiovascular diseases, respiratory diseases, and from unnatural causes such as suicide, injuries from violence or other traumatic events, and accidents (Mazi-Kotwal & Upadhyay, 2011). According to one recent report, “only 80% of people with schizophrenia die from natural causes, for example, compared with 97% of the general population. The higher rates of these deaths are largely attributable to accidents and suicide, which tend to occur more often in early than late adulthood” (Thornicroft, 2011).

In addition to the direct mortality from these conditions, people with serious mental illnesses receive poorer care and this can lead to morbidity and mortality from a wide range of conditions (Lawrence & Kisely, 2010). Most of the deaths from natural causes experienced by people with serious mental illnesses can be attributed to the effects of smoking and obesity, although other factors lead to illness and death as well. Yet, there are disparities in screening for diseases such as cancer in people with serious mental illnesses with obvious consequences for mortality (Howard, Barley, Davies, Rigg, et al., 2010).

There are far reaching societal implications as well. Inequalities in health care and other essential services undermine the social fabric that holds societies together and can ultimately lead to societal unrest and uprisings as seen recently in several countries around the world. Such inequalities can contribute to higher levels of mental illness, further impacting those involved and draining additional financial resources from health care systems that are increasingly under funded (Canadian Mental Health Association & Wellesley Institute, 2009). Although not a panacea for all of society’s ills, ensuring equity in physical and mental health treatment has implications for all segments of society, not just those affected by serious mental illnesses (Canadian Mental Health Association & Wellesley Institute, 2009; U.S. Department of Health and Human Services, 2011).

### **Deaths from Natural Causes – Smoking and Obesity**

The excess rate of death from natural causes is primarily attributable to the effects of smoking and obesity, which lead to the respiratory diseases, cancers of many kinds, diabetes, and cardiovascular diseases, that ultimately cause premature disability and death (Parks, Svendsen, Singer & Foti, 2006). Although it is important to encourage lifestyle changes to reduce the risk of illness and death, there are complicated physiologic mechanisms at work that make smoking cessation and weight loss for this population exceedingly difficult.

#### *Smoking*

People with serious mental illnesses frequently have co-morbid substance use disorders and when taken together, these individuals account for almost half of the Americans who die annually from smoking related disorders (Schroeder & Morris, 2010). These individuals



also consume forty four percent of all cigarettes sold in the U.S. They have higher smoking rates and smoke more cigarettes per day (Lasser, Boyd, Woolhandler, Himmelstein, et al., 2000). Generally speaking, the more severe the mental illness, the higher the smoking prevalence (DeLeon & Diaz, 2005; Grant, Hasin, Chou, Stinson, et al., 2004; Lasser, Boyd, Woolhandler, Himmelstein, et al., 2000). Many of those with serious mental illnesses are very poor, and cigarettes consume a large proportion of their discretionary spending. An additional factor is that it is harder to achieve community integration when also experiencing stigma related to tobacco use (Schroeder & Morris, 2010).

The reasons why people with serious mental illnesses use cigarettes at such a high rate are many and varied. Cigarette smoking has been promoted in most cultures for generations and the U.S. is no exception. Cigarettes were given to U.S. soldiers during the World Wars, Korean War, and the Vietnam War, effectively addicting many who served. The practice was ultimately stopped due to pressure from health advocates (Blake, 1985) but the cigarette industry continued to lobby for preferential pricing in military commissaries around the world (Joseph, Muggli, Pearson & Lando, 2005; Smith, Blackman & Malone, 2007).

Research into the physiologic reasons for the high rates of smoking in this population is quite recent and the answers are not yet fully known. Genetic research has found an association with certain chromosomes and the nicotine receptor gene in people with schizophrenia and bi-polar disorder (Leonard, Adler, Benhammou, Berger, et al., 2001). This receptor gene has been implicated in impaired sensory processing in individuals with schizophrenia and schizo-affective disorder (Martin & Freedman, 2007). It has been hypothesized that there is a therapeutic effect of smoking for people with serious mental illnesses because nicotine is thought to normalize the deficits in sensory processing, attention, cognition and mood (George, Termine, Sacco, Allen, et al., 2006; Sacco, Bannon & George, 2004). Nicotine may also offer some relief from the side effects of psychotropic medications because smoking decreases blood levels of these drugs (Ziedonis, Williams & Smelson, 2003).

In addition to the above, smoking also offers the same rewards that it does for the general population, i.e., reduction in stress, anxiety, and boredom, and opportunities for social interaction with other smokers. However, the postulated genetic and neurobiologic mechanisms coupled with the highly addictive properties of nicotine, may be the reason why smoking is so prevalent and why, for this population in particular, it is so difficult to stop.

### *Obesity*

Like smoking and the neurobiologic effects of nicotine, weight gain in people with serious mental illness is not a simple matter. The physiologic interplay between the causes of obesity, diabetes, and metabolic syndrome in people with serious mental illnesses is highly complex. While the ultimate effects of these factors (increased morbidity and mortality) are

known, the relationships between the underlying factors are only beginning to be understood.

Obesity is far more prevalent in people with serious mental illnesses than in the general population (Dickerson, Brown, Kreyenbuhl, Fang, et al., 2006; Parks, Svendsen, Singer & Foti, 2006). This can be due to a variety of reasons including poor nutrition, poverty making it difficult to purchase healthy foods, being homeless or inadequately housed making it difficult to prepare nutritious meals, cognitive deficits that make it difficult to understand and process the importance of healthy eating, and arguably most importantly, due to the iatrogenic effects of psychotropic medications, especially the second generation anti-psychotics, most particularly clozapine and olanzapine, which induce weight gain. Medications for bi-polar disorder such as valproic acid and lithium can also cause weight gain in people using these drugs, especially when used in combination with the second generation anti-psychotics.

Becoming overweight and obese leads to musculoskeletal disorders, pain and difficulties in getting adequate exercise, which in turn can lead to diabetes, insulin resistance, and cardiovascular disorders, and these can ultimately lead to metabolic syndrome with its increased risk of type 2 diabetes, heart attack, and stroke (Parks, Svendsen, Singer & Foti, 2006). The Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) study found that people using antipsychotic medications had much higher rates of metabolic syndrome than people in the general population (McEvoy, Meyer, Goff, Nasrallah, et al., 2005), putting them at significantly greater risk of the cardiovascular events that can result from the syndrome. Recent research has also suggested that second generation anti-psychotic medications may put people at risk of sudden cardiac arrest and death (Manu, 2011).

A recent meta-analysis of the research literature on this topic found that the prevalence of metabolic syndrome in people with schizophrenia and related disorders is consistent across treatment setting (inpatient vs outpatient), country of origin, and gender. Older individuals were at greater risk but those who had been ill the longest had the highest risk of developing the syndrome. When individual studies were evaluated, waist size was most useful in predicting metabolic syndrome and use of antipsychotic medication, especially clozapine, conveyed the highest risk. Those who did not use anti-psychotic medications were at lowest risk of this life threatening syndrome (Mitchell, Vancampfort, Sweers, van Winkel, Yu & de Hert, 2013).

Like smoking, losing weight for people taking anti psychotic medications has proven to be very difficult. When the fact that psychotropic medications induce weight gain is considered, it is easy to understand why losing weight for this population has proven to be so extremely difficult. The following from an article entitled "Do we truly appreciate how difficult it is for patients with schizophrenia to adapt a healthy lifestyle?" sums these issues up concisely:

Their efforts to eat healthfully are undermined by the appetite stimulating effect of their medications. Besides, the atypical antipsychotic medications may also promote their responsiveness to external eating cues. For these patients quitting smoking is also harder than it is for individuals without schizophrenia. Nicotine provides greater stimulation and state-enhancement for them than it does for healthy individuals. They also have a poorer appreciation of the risks associated with smoking. Recurrent episodes of acute psychosis are frequent in patients with schizophrenia and disrupt any efforts they might make towards a healthful lifestyle.... What is unique to patients with schizophrenia is their greater difficulty in breaking the pattern of unhealthful lifestyle and preventing its consequences due to factors related to their illness and its treatment (Hasnain, Victor & Vieweg, 2011).

Recent research has identified that pharmacologic interventions may be helpful in preventing or reducing weight gain associated with anti-psychotic medications (Mahmood, Booker, Huang & Coleman, 2013).

Because of the serious health implications associated with smoking and obesity, and the great difficulty that people with serious mental illnesses have in reducing these risk factors, individuals should be monitored very closely for early signs of respiratory and cardiovascular disorders, for cancers of all kinds, and provided with the newest and best pharmacologic interventions available.

### **Deaths from Unnatural Causes – Suicide and Violence**

Although most deaths are from natural causes (Brown, Kim, Mitchell & Inskip, 2010), people with serious mental illnesses are also at increased risk of dying from unnatural causes including suicide, violence and accidents, with the majority attributable to suicide and violence (Harris & Barraclough, 1997; Hiroeh, Appleby, Mortensen & Dunn, 2001; Ösby, Correia, Brandt, Ekblom, et al., 2000). Use of alcohol and other drugs is often a complicating factor, especially in accidental deaths (Bossarte, Simon & Barker, 2006; Khalsa, Salvatore, Hennen, Baethge, et al., 2008). Moreover, rates of premature death from suicide and violent crime have been increasing compared to the general population since the 1970s. This same study also found that compared to the general population, both men and women with schizophrenia were eight times more likely to die prematurely (before age 56), highlighting the need for much closer follow up and better treatment for this population who are at substantially elevated risk of adverse outcomes (Fazel, Wolf, Palm & Lichtenstein, 2014).

#### *Suicide*

For people with serious mental illness, the risk of suicide is 9 – 10 times greater than the risk for people in the general population (Harris & Barraclough, 1997; Harris & Barraclough, 1998). Several risk factors have been consistently identified. These include previous suicide attempt or previous attempts to harm oneself, presence of depressive symptoms, involvement with the police, and being a young male at time of inpatient admission,

(Appleby, Dennehy, Thomas, Faragher, et al., 1999; Bakst, Rabinowitz & Bromet, 2010; Kan, Ho, Dong, Dunn, 2007; King, Baldwin, Sinclair, Baker, et al., 2001; McKenzie & Wurr, 2001; Sinclair, Mullee, King & Baldwin, 2004).

People are most at risk immediately following discharge from the hospital, and within ninety days of discharge, especially for those discharged from a first admission (Appleby, Dennehy, Thomas, Faragher, et al., 1999; Lee & Lin, 2009) and the risk is greater for those without a previous admission during the year, compared to those hospitalized more than three times in the previous year (Geddes & Juszczak, 1995; Goldacre, Seagroatt, Hawton, 1993; Heila, Isometsa, Henriksson, Heikkinen, et al., 1997; Lee & Lin, 2009).

Other than outreach and close follow up, few preventive measures have been identified, although high levels of support have been shown to reduce risk (Sinclair, Mullee, King & Baldwin, 2004).

### *Violence*

People with serious mental illnesses are at increased of violence in the community (Brekke, Prindle, Bae & Long, 2001) and are exposed to high rates of interpersonal violence (Carmen, Rieker & Mills, 1984; Greenfield, Strakowski, Tohen, Batson, et al., 1994; Goodman, Salyers, Mueser, Rosenberg, et al., 2001; Lipschitz, Kaplan, Sorkenn, Faedda, et al., 1996; Mueser, Goodman, Trumbetta, Rosenberg, et al., 1998; Mueser, Salyers, Rosenberg, Goodman, et al., 2004). Those with mental illnesses are at much greater risk of homicide. Reasons for this include the fact that people with mental disorders are frequently very poor and often live in deprived areas with high crime rates, their symptoms may cause them to be less aware of risks to their own safety, and people with serious mental illnesses are often thought of as dangerous (Crump, Sundquist, Winkleby & Sundquist, 2013), potentially sparking attacks from others who are fearful.

People with serious mental illnesses are also sometimes perpetrators of aggression and violence, especially when they have not received treatment and are under the influence of alcohol and other drugs. The risk of retribution and increased fear and stress, can lead to the possibility of further escalating violence both to themselves and to others (Wehring & Carpenter, 2011). The risk of an individual committing a homicide is greater during the first episode of psychosis and for those who have not received treatment (Nielssen & Large, 2010). However, people with serious mental illnesses are much more often the victims of violence, with victimization of individuals with these illnesses found to be more than four times the incidence in the general US population (Choe, Teplin & Abram, 2008; Teplin, McClelland, Abram & Weiner, 2005).

Engaging people in treatment as soon as symptoms are observed is highly important. Receiving timely medical treatment has consistently been found to reduce the risk that an individual will commit a homicide or suicide (Coid, 1983; Fazel & Grann, 2004; Meehan, Flynn, Hunt, et al., 2006; Nielssen, Westmore, Large & Hayes, 2007; Wallace, Mullen, Burgess, Palmer, et al., 1998). It has further been shown that the second-generation

antipsychotics clozapine, risperidone, and olanzapine significantly decreased violent behavior, while conventional antipsychotics did not have the same effect (Swanson, Swartz & Elbogen, 2004). Unfortunately, there are often delays in accessing treatment for people experiencing their first episode of psychosis, putting them and others at risk.

In addition to psychotropic medication, a recovery oriented, person centered approach to engaging people to recognize their illness and take part in psychosocial rehabilitation interventions such as CBT, skills training, illness management, and family psychoeducation, are important for helping individuals with serious mental illnesses to gain control of their illness and their lives, identify the goals they wish to accomplish, and achieve a satisfying life.

Although there are many factors that influence functional outcomes, there is growing evidence that early intervention with pharmacologic and psychosocial interventions during the first episode of psychosis may lead to improved longterm outcomes (Bertelsen, Jeppesen, Petersen, Thorup, et al., 2008; Bird, Premkumar, Kendall, Whittington, et al., 2010; Ehmann, Yager & Hanson, 2008; Marshall & Rathbone, 2011; McGlashan, Evensen, Haahr, et al., 2011; Tandon, Keshavan & Nasrallah, 2008) and may prevent or delay relapse (Álvarez-Jiménez, Parker, Hetrick, McGorry, et al., 2011).

Risks for both suicide and violence are greater during the first episode of psychosis and for those who have not received treatment. Given that this appears to be a critical period for these events, greater awareness of the prodromal signs and their implications should be provided to general practitioners and the general public to encourage early intervention.

## **Treatment Disparities for Racial and Ethnic Minorities**

Following publication of the Surgeon General's 1999 Report (U.S. Department of Health and Human Services, 1999), it was recognized that disparities in mental health and physical health care are influenced by a variety of factors, including the race/ethnicity of the individual. As a result of this recognition, a Supplement to the Surgeon General's report was published that looked specifically at culture, race and ethnicity (U.S. Department of Health and Human Services, 2001). This Supplement spawned an increase in research on, and publications about the impact of these mediating variables on mental health care in the U.S.

The Supplement summed the situation up concisely:

Racial and ethnic minorities have less access to mental health services than do whites. They are less likely to receive needed care. When they receive care, it is more likely to be poor in quality.... A major finding of this Supplement is that racial and ethnic minorities bear a greater burden from unmet mental health needs and thus suffer a greater loss to their over-all health and productivity (U.S. Department of Health and Human Services, 2001, p. 3).

Virtually every publication on this topic since the Supplement has concluded that substantial differences remain in the way that people from racial and ethnic minorities are treated compared to the way that people from non-minority groups are treated (Alexandre, Martins & Richard, 2009; Atdjian & Vega, 2005; Compton, Ramsay, Shim, Goulding, et al., 2009; Kilbourne, Switzer, Hyman, Crowley-Matoka, et al., 2006; Mallinger, Fisher, Brown & Lamberti, 2006; Rost, Hsieh, Xu, Menachemi, et al., 2011; Snowden, 2003; Whitley & Lawson, 2010; Williams & Mohammed, 2009).

The issues and findings are complex. Some studies have found differences for one group but not for another and at times the findings of one study conflict with the findings of another study. The findings are also complicated by the fact that there are differences in some physicians' attitudes toward people from non-majority racial and ethnic backgrounds. Additionally, there are consumer differences related to factors such as a person's willingness to seek treatment, interest in remaining in treatment, willingness and or ability to fill prescriptions, socioeconomic status and the multitude of factors that SES affects and that in turn affect SES, including availability of health insurance (Atdjian & Vega, 2005; Canadian Mental Health Association & Wellesley Institute, 2009; Graham, 2007; Veling, Selten, Susser, Laan, et al., 2007; Wilkenson & Pickett, 2009). All of these make presentation of a consistent pattern challenging.

Although there are many different racial and ethnic groups in North America, most of the literature is centered on African Americans and Hispanics. The most consistent findings relate to provision of treatment based on published guidelines, including appropriate prescribing practices, and provision of care in appropriate settings.

#### *Guideline Based Treatment*

Several studies have found that both African Americans and Hispanics are less likely to receive treatment that is based on established guidelines (Wang, Berglund, Kessler, 2001; Wang, Demler, Kessler, 2002; Whitley & Lawson, 2010; Young, Klap, Sherbourne & Wells, 2001). With respect to prescription of antipsychotic medication, ethnic minorities have been found consistently less likely than non-ethnic minorities to be treated with newer antipsychotic medications (Puyat, Daw, Cunningham, Law, Wong, Greyson & Morgan, 2013). One finding was quite consistent: African Americans often do not receive appropriate medications or the appropriate dose of a medication. Some studies indicate that African Americans are less likely to receive antipsychotic medication (Mallinger, Fisher, Brown & Lamberti, 2006) and some studies have indicated that when these medications are prescribed, the dosages are higher than they should be (Blazer, Hybels, Simonsick & Hanlon, 2000; Chung, Mahler & Kakuma, 1995; Kuno & Rothbard, 1997; Lawson, 1999; Melfi, Croghan, Segal, Bola & Watson, 2000; Sclar, Robinson, Skaer & Galin, 1999; Snowden & Pingatore, 2002; Walkup, McAlpine, Olsson, Labay, et al., 2000). Relatedly, some studies have found that African Americans are diagnosed more frequently with schizophrenia (although it has also been suggested that this could be due to the way symptoms are presented) and Hispanics are diagnosed more frequently with depression. It has also been

reported that African Americans often receive higher doses of antipsychotic medication while Hispanics often receive lower doses of these medications (Atdjian & Vega, 2005).

### *Treatment Settings*

Another consistent finding is that African Americans are over-represented in non-forensic in-patient settings and in emergency room departments (Snowden, 1999). Both African Americans and Hispanics are over-represented in forensic psychiatric hospitals and in jails and prisons. As is widely recognized, these settings have become some of the largest treatment venues in the U.S. for people with serious mental illnesses (Lindsey & Paul, 1989; Rosenhan, 1984; Whitley & Lawson, 2010). These issues are discussed in detail in the Forensics modules of this curriculum.

## **What are the Reasons for Disparities in Care?**

Many of the reasons for the disparities in care are similar whether one considers the differences between physical and mental illness or the differences between minority and non-minority groups. While the original Report of the Surgeon General (U.S. Health and Human Services, 1999) highlighted some of these reasons, the Supplement to the Report (U.S. Department of Health and Human Services, 2001) focused to a much greater extent on the reasons behind these disparities.

As pointed out by the Supplement to the Surgeon General's Report, more is known about the disparities in treatment than the reasons behind those disparities. The Supplement proposed several likely reasons as follows:

The foremost barriers include the cost of care, societal stigma, and the fragmented organization of services. Additional barriers include clinicians' lack of awareness of cultural issues, bias, or inability to speak the client's language, and the client's fear and mistrust of treatment. More broadly, disparities also stem from minorities' historical and present day struggles with racism and discrimination, which affect their mental health and contribute to their lower economic, social, and political status (U.S. Department of Health and Human Services, 2001, p 4).

Related to the reasons mentioned by the Surgeon General's Supplement, several reasons have been proposed in the literature. These include lack of insurance, mis-communication or mis-perceptions of providers due to language or other cultural factors, bias of providers toward people with serious mental illnesses and those from minority racial and ethnic backgrounds, and challenges presented by the characteristics of the population itself.

### *Lack of Insurance*

People with serious mental illnesses are most often poor, unemployed, and lack health insurance. Many people also are homeless or inadequately housed. If they are working, they may be earning so little that they fall just above the eligibility line for Medicaid, but without access to health insurance, making access to other than emergency health care

extremely difficult. Without access to health care, they may end up in emergency rooms or in jail when treatment is needed, and this can ultimately lead to a worsening of their mental health condition (Atdjian & Vega, 2005; Graham, 2007; Wilkinson & Pickett, 2009). Delays in receiving treatment due to lack of health insurance have also been reported for young people with emerging psychoses (Compton, Ramsay, Shim, Goulding, et al., 2009). As noted earlier in this module, delays in first episode treatment have been related to violence and homicide for this population, making early intervention an issue of considerable importance.

### *Cultural Factors*

There can be many reasons for miscommunication. Many people in North America come from countries where English is not the first language and may not even be spoken. In addition to difficulties with language, there are many other ways that culture can have an impact on what is communicated. Some cultures do not acknowledge the existence of mental illnesses or acknowledge their existence only in certain circumstances. Within some cultures, there is great stigma associated with mental illness; for others, there are gender differences in acceptability of different illnesses (Alegria, Canino, Rios, Vera, et al., 2002; Kung, 2004; Leong & Lau, 2001). Mis-understanding due to translation problems is another potential difficulty (Baker, Hayes & Fortier, 1998; David & Rhee, 1998). Establishing trust can require overcoming reluctance and fear due to years of prior mis-treatment or prejudice (Akutsu, Snowden & Organista, 1996; Snowden, Hu & Jerrell, 1999; Takeuchi, Sue & Yeh, 1995; Yeh, Takeuchi & Sue, 1994).

### *Practitioner Bias*

Practitioner bias such as holding beliefs and expectations about members of a certain group or population has been suggested as one of the major reasons why people with serious mental illnesses and people from racial and ethnic minorities receive sub-standard care (Ahn, Proctor & Flanagan, 2009; Atdjian & Vega, 2005; Osborne, 2001; Snowden, 2003). Most bias is subtle and often providers do not even recognize that they are biased (Burgess, van Ryn, Dovidio & Saha, 2007), but there is abundant evidence that physicians and other providers hold biases that impact their interpretation of presenting behaviors and symptoms, and that subsequently impact on the clinical judgments they make (Moy, Dayton & Clancy, 2005). Provider bias can be especially important when consumer characteristics such as poverty, reluctance to accept treatment, take medications, or “adhere” to recommendations are expressed (Mazi-Kotwal & Upadhyay, 2011; Snowden, 2003). One difficulty with overcoming bias is that practitioners are reluctant to admit that they are biased, even if they do realize it. Sensitivity and cultural competence training have been recommended but these have not always achieved the desired results (Burgess, van Ryn, Dovidio & Saha, 2007).



## *Challenges Presented by People with Serious Mental Illnesses*

There are several challenges presented by people with serious mental illnesses. Individuals are often suspicious of mental health professionals (and often with good reason), and they may not want to have anything to do with the mental health system. The pervasive effects of stigma and the vulnerability of individuals who are ill can make it difficult for them to seek help (Mazi-Kotwal & Upadhyay, 2011; Thornicroft, 2011), or they may miss appointments or drop out of treatment (Atdjian & Vega, 2005). Individuals can sometimes present as hostile, fearful and uncooperative. These behaviors can reinforce a provider's biases and can make interactions highly charged and difficult. These factors can make it challenging for mental health providers to know how to be of assistance (Phelan, Stradins & Morrison, 2001). When racial and ethnic differences or language barriers are added, the result can be less than optimal and potentially damaging for the person who needs assistance, ultimately leading to the observed disparities in treatment.

## **Challenges**

People with serious mental illnesses face many difficult challenges which can lead to the observed disparities in health care and early death rates seen in this population. The illnesses themselves present challenges that are daunting and in many cases, alter the course of the individual's life. There are also challenges associated with the prescribed treatment and with the service delivery system and providers within those systems.

The challenges for psychologists and other mental health providers lie in helping people with serious mental illnesses benefit from smoking cessation and weight loss interventions. Encouragement is needed to help people connect the reasons for quitting smoking, losing weight, etc. to the achievement of their life goals. Despite the very real difficulties people with serious mental illness who want to avoid smoking and weight gain, some have achieved success.

Provision of person centered engagement, assessment and treatment planning is essential and must include a focus on the importance of life style changes as a means for achieving the kinds of roles and lives that each person hopes to accomplish. Encouraging people and supporting them to remain in intervention programs despite the difficult impediments to success is crucial. Psychologists can also encourage their research colleagues to seek answers to overcome the physiologic inhibitors to smoking cessation and weight loss. Psychologists and other practitioners should challenge themselves and their colleagues to ensure that the most appropriate and up to date treatment is provided and to ensure that biases and prejudice are overcome. Psychologists and other practitioners should also work to change the systemic factors that contribute to failures of the mental health service system which allow these known health disparities to continue.

## Summary

There are considerable disparities faced by people with physical health conditions and serious mental illnesses. On average, people who have a serious mental illness die twenty to twenty five years earlier than those without such an illness. The reasons for this are complex and research continues to disentangle the effects of various contributing factors.

Smoking and obesity are among the most important factors but these are intertwined with the neurobiologic mechanisms of the disorders and the medications used to treat them. Although not fully understood, two of the most serious side effects of antipsychotic medications are the hypothesized therapeutic effects of smoking, and medication induced weight gain. Both smoking and gaining weight have been shown to be highly resistant to change due to factors associated with the illness itself and the medications used to treat the illnesses.

There are additional issues faced by people from racial and ethnic minority backgrounds. Most of the available published literature centers on African Americans and Hispanics who have been shown to receive poorer quality treatment that is not based on published guidelines. Findings specific to treatment failures for minority persons include incorrect diagnoses, inappropriate medication dosing, and overuse of confinement in inpatient or forensic/jail settings.

In addition to the physiologic reasons that encourage smoking and weight gain, there are systemic reasons for the observed health disparities. The reasons range from personal and treatment system failures to issues presented by individuals with serious mental illnesses. Included are provider biases against people with serious mental illnesses and/or people from racial and ethnic minority backgrounds, failure to provide adequate and appropriate care due to cultural differences, poverty and lack of health insurance (in the U.S.), and delays in receiving treatment. Delays in receipt of treatment can be due to provider failures to recognize and offer appropriate treatment or due to individual and family delays because of previous negative experiences with the treatment system or lack of awareness and understanding of the illness and the need for intervention. Delays in treatment especially for the first episode of psychosis can be particularly problematic due to the heightened risk of suicide and violence for people with untreated psychoses.

Psychologists and other mental health providers need to strongly encourage people with serious mental illnesses to remain in smoking cessation and weight loss intervention programs despite the difficult impediments to success. Additionally, we need to challenge the personal and systemic factors that contribute to failures of the mental health service system that allow these known health disparities to continue. Finally, we need to encourage individuals to take charge of their health care and assist individuals to learn about and participate in wellness activities and practices.

## Sample Learning Activity

There are two parts to this activity. The instructor(s) should take part in the exercise along with the students. The instructions for the second part of the activity are not to be given out until it is time to begin the second part.

General directions: The purpose of this role play is for students to understand the role that culture can play in a person's interactions with the health care system and how those interactions may lead to incorrect or inappropriate diagnoses and treatment recommendations. Individuals can be misunderstood, dismissed, diagnosed incorrectly, etc. because in real life situations, time is often not taken to do things adequately. The person playing the consumer should respond as he or she believes a person would, i.e., if recovery oriented approaches are used, then the consumer might respond in kind, whereas if terse, medically oriented approaches are used, the person might feel misunderstood and respond accordingly. As little direction as possible should be given – the most important thing is that everyone should respond as genuinely as possible.

Part I: Depending on the size of the group, the large group is divided into two small groups. If the overall group is small, one group of 5 or 6 should be used. One or more volunteers will play the part of a person with a serious mental illness (one for each group). It is preferable if the volunteers actually know someone or has had experience with someone who has a serious mental illness so that their portrayal can be more genuine. If there is only one small group, the part of the young man below should be acted. If there are two small groups, one consumer actor will play the young man in the scenario below and the other consumer actor will play a young Hispanic woman, originally from Mexico. The details remain the same for both the young man and the young woman.

The consumer is a young black man, between 18 and 24 years old, originally from Somalia, who speaks with a heavy accent and who appears confused and “a bit out of it”. He has been using drugs to “take the away the pain in his head”. He has been living on the streets because he was thrown out of the last several places he was living due to his erratic behavior. He does not have contact with his family as he believes they are trying to kill him.

The person has been brought to the emergency room of the local hospital or clinic because he has been wandering around the streets late at night, talking to himself using obscenities and appearing to be angry and hostile.

Each of the non-consumer actors in the small group will play one of the following parts:

The admitting nurse

The evaluating psychologist

The prescribing psychiatrist

The peer support worker

The consumer actor should stay in the role to the greatest extent possible but should also follow his instincts about how to react to each of the other actors. Beginning with the nurse, each non-consumer actor will have a five minute conversation with the person and will formulate an opinion and recommendation that will be shared later. The finding is to contain the following elements:

a) initial diagnosis (recognizing that a real person centered interaction would take much longer than the time available in this role play), b) recommendation, and c) immediate plan of action

Part II: At the conclusion of the role play, all members of the group (or small group if divided) are to discuss the following (the following instructions should now be handed out to each participant):

1. What barriers to effective communication and participation in each of the consultations were there? What strategies were used to address these barriers? What other strategies could have been used?
2. What were the issues around capacity, decision making and consent in relation to this person?
3. How did the consumer actor feel during the interviewing process? Did he believe his concerns were genuinely heard?

The group should discuss each of the diagnoses, recommendations, and action plans that were offered. The consumer actor should indicate whether or not he felt that his true situation was recognized and whether or not the diagnosis, recommendation, and action plan of each of the actors will be helpful to someone in his situation.

## Sample Evaluation Questions

### Question

### Correct Answer

1. The primary causes of death for people with serious mental illnesses include:

- a) smoking and obesity
- b) cardiovascular diseases, respiratory diseases, and cancer
- c) suicide and violence
- d) all of the above
- e) a and c above
- f) b and c above

f is correct

2. For African Americans in the mental health service delivery system, the following are true:

- a) they are overly represented in in-patient settings and emergency room departments
- b) they are overly represented in forensic and other correctional venues
- c) they often receive inappropriate medications or inappropriate medication dosages
- d) b and c above
- e) all of the above

e is correct

True False

3. Smoking cessation and weight loss programs save lives and have been shown to be highly effective for people with serious mental illnesses

F

4. People with serious mental illnesses are at greater risk of death from suicide and homicide during the initial stages of psychosis and when the illness is left untreated

T

5. People from racial and ethnic minority backgrounds have less access to care, receive poorer quality care, and suffer a greater loss to their overall health and productivity than do people from non minority backgrounds

T

## Lecture Notes Citations

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## **Additional Resources**

American Psychological Association Recovery to Practice Initiative.  
<http://www.apa.org/pi/rtp>

## Citing the Curriculum

Citation for this Module:

American Psychological Association & Jansen, M. A. (2014). Health Disparities. *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

Citation for the full Curriculum:

American Psychological Association & Jansen, M. A. (2014). *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

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# American Psychological Association

## Recovery to Practice Initiative Curriculum: Reframing Psychology for the Emerging Health Care Environment

### *7. Interventions I: Guiding Principles and Integrated Framework*

**NOTE:** There are three Interventions modules. They are designed to be used together and are not intended to be used separately or as stand alone modules

August 2014

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## Overview

This is the first of three modules on intervention services. The three modules are designed to be used together; they cannot stand alone as the content of any one is not sufficient to understand or provide Psychosocial Rehabilitation (PSR) interventions.

In Interventions I, the guiding principles that underlie the provision of all PSR services are discussed along with an integrative framework model that can be used to coordinate PSR services. The guiding principles are essential for the successful implementation of the interventions discussed in Interventions II and Interventions III. In Interventions II, interventions that have been proven through empirical research to achieve specific outcomes are presented; these are known as evidence based practices (EBPs). In Interventions III, interventions that have shown promise of achieving specified outcomes are presented; these are known as promising or emerging practices. Interventions III also presents supporting services that are widely acknowledged to be essential services for helping people recover from the effects of serious mental illness.

## Learning Objectives

At the end of this module you will be able to:

- Identify at least three of the guiding principles for PSR interventions
- Describe four positive outcomes research has identified that result from involving consumers in a shared decision making process
- Describe at least four of the components of the process presented by the integrative framework for provision of PSR interventions
- List the two foci upon which PSR interventions are based

## Resources

- Lecture Notes
- Required Readings
- Lecture Notes Citations
- Sample Learning Activity
- Sample Evaluation Questions
- Additional Resources

## Required Readings

Bellack A. (2006). Scientific and consumer models of recovery in schizophrenia: Concordance, contrasts, and implications. *Schizophrenia Bulletin*, 32, 3, 432–442.

Farkas, M. & Anthony, W. A. (2010). Psychiatric rehabilitation interventions: A review. *International Review of Psychiatry*, 22, 2, 114–129.

## Activities

Complete the following activities:

- Read the lecture notes
- Read the required readings
- Engage in a learning activity related to this module
- Evaluate students' understanding of this module.

## Lecture Notes

People with lived experience of serious mental illness are strongly encouraged to be part of the delivery of the curriculum including being active participants in the delivery of the lecture. Refer to the curriculum Instruction module for additional information.

### Introduction

As described in previous modules, studies over the past several decades have shown that many adults with serious mental illnesses can and do recover when they are provided with supports and services that assist them to gain the skills needed to live a satisfying and productive life. In fact, despite long held beliefs that serious mental illnesses are chronic deteriorating illnesses, several meta analyses and summaries of recently conducted studies have appeared and all continue to document that individuals with serious mental illnesses can, and do recover from the effects of their illness (Warner, 2010), and indeed that most have the potential to achieve long-term remission and functional recovery (Zipursky, Reilly & Murray, 2012).

Users of mental health services have consistently said that they want the same things for themselves that every citizen wants: a family, a safe place to live, meaningful activities, adequate income, job satisfaction, and an enjoyable social life. For people with serious mental illness, attainment of life goals often requires substantial assistance in the form of specially designed psychosocial rehabilitation (PSR) services. While some people with serious mental illness may recover without assistance, many are unable to recover sufficiently to achieve the quality of life that they desire without these specialized services (Silverstein, 2000).

This module of the curriculum does not provide information about specific PSR services. Information about PSR services is provided in the Interventions II module and in the Interventions III module. Rather, this module will discuss the underlying values and characteristics that underlie the provision of PSR services and that must be present to achieve a recovery oriented system of services.

The knowledge base about the range of interventions shown to be effective and the importance of the underlying values and principles have developed considerably over the past twenty five to thirty years. Despite the considerable advances in our knowledge of what can be helpful to people with serious mental illness, there is much that remains unknown. For example, while we have a range of interventions based on empirical research, i.e., evidence based practices (EBPs), that have been shown to be effective in helping people with serious mental illness achieve certain specified outcomes, we know very little about the multitude of factors that can, and often do, impact on the successful provision of these services. The following are but a few examples of these unknown variables:

- The settings in which the interventions are most efficacious

- How to implement the practices successfully especially in light of resource constraints
- Whether or not all of the components of the EBPs are necessary for success
- The contribution of underlying constructs and values such as provider characteristics, relationship with the person(s) being served
- The required minimal training levels of providers
- Possible interactions between stage of illness, current symptomatology, and residual capabilities such as executive functioning
- Cultural background of the persons receiving any given intervention
- Intrapersonal characteristics of the individual such as self efficacy, sense of empowerment, etc.

These are but a few of the variables whose impact on the outcome of provision of PSR interventions is unknown. As recently as 2005, authors reinforced the need for better evidence of the impact of interventions on recovery outcomes:

Recovery is an emerging movement in mental health. Evidence for recovery-based approaches is not well developed and approaches to implement recovery-oriented services are not well articulated (Oades, Deane, Crowe, Lambert, et al., 2005).

Despite this, mental health practitioners agree that the underlying values accepted as essential for effective clinical practice should be incorporated into interventions designed to assist people in their recovery from serious mental illness. For example, provision of services within the context of an empathic, genuine, trusting relationship where the person with serious mental illness is involved in a partnership to agree on and design the components of services he or she will receive, is generally considered to be important for the success of recovery oriented interventions (Anthony, Rogers & Farkas, 2003; Mueser, 2012). The importance of these for provision of effective mental health services was articulated several decades ago (Carkhuff, 1969; 1980; Rogers, 1957; Truax & Carkhuff, 1967) and remains relevant today (Miller & Rose, 2009).

## **Guiding Principles of PSR Interventions**

Provision of PSR services rests on a platform of principles that are seen as essential for successful outcomes. In addition to the values mentioned above (empathy, trust, genuineness and involvement of people in decisions about their health care), we know that services must be guided by the following:

- Recognition that recovery and return to a satisfying and productive life are possible;
- Provision of interventions that are grounded in research and achieve results;

- Acceptance that, to the greatest extent possible, those with serious mental illnesses and their families are full partners with the service delivery system and determine the services they will receive.

Several principles have been identified as important for provision of effective recovery oriented services. These were originally specified by participants in the National Consensus Conference on Mental Health Recovery and Transformation (U.S. Department of Health and Human Services, 2006) and recently updated to reflect the importance of culture, trauma, and inclusion in family and social networks. These are:

Recovery emerges from hope: The belief that recovery is real provides the essential and motivating message of a better future – that people can and do overcome the internal and external challenges, barriers, and obstacles that confront them.

Recovery is person-driven: Self-determination and self-direction are the foundations for recovery as individuals define their own life goals and design their unique path(s) towards those goals.

Recovery occurs via many pathways: Individuals are unique with distinct needs, strengths, preferences, goals, culture, and backgrounds – including trauma experiences – that affect and determine their pathway(s) to recovery.

Recovery pathways are highly personalized: They may include professional clinical treatment; use of medications; support from families and in schools; faith-based approaches; peer support; and other approaches.

Recovery is non-linear, characterized by continual growth and improved functioning that may involve setbacks.

Recovery is holistic: Recovery encompasses an individual's whole life, including mind, body, spirit, and community.

Recovery is supported by peers and allies: Mutual support and mutual aid groups, including the sharing of experiential knowledge and skills, as well as social learning, play an invaluable role in recovery.

Recovery is supported through relationship and social networks: An important factor in the recovery process is the presence and involvement of people who believe in the person's ability to recover; who offer hope, support, and encouragement; and who also suggest strategies and resources for change.

Recovery is culturally-based and influenced: Culture and cultural background in all of its diverse representations - including values, traditions, and beliefs - are keys in determining a person's journey and unique pathway to recovery. Services should be culturally grounded, attuned, sensitive, congruent, and competent, as well as personalized to meet each individual's unique needs.

Recovery is supported by addressing trauma: The experience of trauma (such as physical or sexual abuse, domestic violence, war, disaster, and others) is often a precursor to or associated with alcohol and drug use, mental health problems, and related issues.

Recovery involves individual, family, and community strengths and responsibility: Individuals, families, and communities have strengths and resources that serve as a foundation for recovery.

Recovery is based on respect: Community, systems, and societal acceptance and appreciation for people affected by mental health and substance use problems – including protecting their rights and eliminating discrimination – are crucial in achieving recovery.

The evidence supporting the importance of these principles for recovery is quite consistent and comes from first person accounts of people who have received services. Whenever consumers are asked about the elements of service provision that made a difference to them, the principles outlined above are often referenced (Deegan, 1988; Jacobson, 2001; Mead & Copeland, 2000; Ridgeway, 2001; Wisdom, Bruce, Saedi, Weis, et al., 2008). To be effective, PSR interventions must be designed with these as the basis for service provision.

### **Consumer Involvement in Planning & Evaluating Services/Shared Decision Making**

While consumer involvement and shared decision making are not interventions, they deserve special mention because they are seen as an integral component of the method for delivering PSR services.

A central premise of recovery oriented practice is that the individual is a full partner in making decisions related to which interventions are desired and deemed to be most useful (Deegan & Drake, 2006). Interventions for people with serious mental illness are provided within a person centered approach with full involvement of the individual receiving services. Professionals may resist full involvement of people with serious mental illness in the decision making process, but research has shown that most individuals prefer shared decision making (Adams, Drake & Wolford, 2007); without such involvement services cannot be considered to be recovery oriented.

Research on involvement in general health care has shown that consumers who believe they have been actively involved in decisions about the services they received generally have better outcomes (Greenfield, Kaplan, Ware, Yano, et al., 1988; Stewart & Brown, 2001). Conversely, those who felt they had little input or control over their services were less likely to be involved with their services, rated their health as poorer, and evidenced greater illness burden (Seeman & Seeman, 1983).

Similarly, active participation by consumers of mental health services has also been shown to have several benefits, including increased satisfaction with services and decreased symptom burden (Adams & Drake, 2006; Swanson, Bastani, Rubenstein, Meredith, et al.,



2007). Research data have also suggested that rehabilitation outcomes are better for people who are partners in the planning and delivery of their services (Majumder, Walls & Fulmer, 1998). Additional benefits have been identified including the person's increased level of knowledge about their condition, increased self efficacy, greater planning for coping with difficult situations, and increased knowledge of alternatives (Patel, Bakken & Ruland, 2008). Consumer involvement in designing and delivering mental health services (e.g., program planning, implementation, and evaluation) is increasingly seen as a critical component of a quality management system for any mental health service (Blackwell, Eilers & Robinson, 2000).

Because there may be times when people with serious mental illness cannot make sound decisions due to symptom flare ups, preparation of an advance directive that provides guidance about the person's preferences in different situations has been recommended (Deegan & Drake, 2006). Most authors also note that research on the complexities and benefits of shared decision making is relatively recent and additional research is recommended (Adams & Drake, 2006; Patel, Bakken & Ruland, 2008).

## **Importance of Gender Specific and Culturally Relevant Services**

Most mental health services, like general health care services, were designed with men from the majority culture in mind. While many assume that a "one size fits all" approach is acceptable, gender and cultural considerations are essential if the service system is to be helpful to those who need services.

### **Services for Women with Serious Mental Illness**

Women are a sizeable proportion of those with serious mental illnesses and are the most vulnerable adults served within the mental health system. The service needs of women clients can be very different than those of men (Bently, 2005). Homeless women are more vulnerable than homeless men, are poorer, and often have additional stressors due to child care responsibilities (Harris & Bachrach, 1990). Women are more likely to have been abused physically, sexually, or both. Due to their increased vulnerability and poverty, women are more likely to be unable to control sexual situations and may be more often exposed to HIV/AIDS and other sexually transmitted diseases (Darves-Bornoz, Lemperiere, Degiovanni & Gaillard, 1995). Women who have experienced violence, abuse and trauma often have co-occurring mental health and substance abuse problems (Ad Hoc Working Group on Women, Mental Health, Mental Illness and Addictions, 2006; Elklit & Shevlin, 2011). In addition, women that have been abused by men will likely be unable to work through those issues in a mixed group and a mixed trauma group can actually exacerbate their trauma. Services offered in women only groups are essential for women who have been abused both to help them recover and to avoid exacerbating their trauma.

## **Culturally Relevant Services**

Mental health and addictions services must also be culturally informed. Mental health problems among non-white, minority cultural groups can be great, and the actual prevalence may be higher than reported due to a reluctance to access services or to report problems. For example, suicide rates among people from Aboriginal backgrounds are three times higher than among the general population, yet the problems often go unreported or untreated (Kirmayer, Hayton, Malus, DuFour, et al., 1993). Cultural discontinuity and oppression have also been linked to high rates of depression, alcoholism, suicide, and violence in many communities, with the most dramatic impact on youth (Kirmayer, Macdonald & Brass, 2000). Lack of culturally and linguistically appropriate services has been reported as a reason for the failure to access services by non-majority groups (Elliott, 2003). Additionally, many culturally distinct groups are not used to speaking frankly about problems and may speak in metaphors or use less descriptive words to describe their life situation or problem (Vasiliadis, Lesage, Adair, et al., 2005). People who are immigrants and/or refugees often face even more serious problems that make accessing services very difficult. A more comprehensive discussion of the problems faced by those who are immigrants and refugees can be found in the Engaging People as Partners module and in the Person Centered Planning module. The problems and issues cited are often not recognized by traditional service providers; this speaks to the importance of outreach to ensure access so that appropriate services are available for all who need them.

## **An Integrative Framework Model for Provision of PSR Interventions**

An overall framework for serving individuals with serious mental illness is a useful way to organize services (Anthony, Cohen, Farkas & Gagne, 2002; Anthony, Howell & Danley, 1984; Farkas & Anthony, 1989). The model presented below is an approach to working with people with serious mental illness and is titled the Choose, Get, Keep method for providing PSR services.

The authors recently offered this conceptualization:

Psychiatric rehabilitation interventions are currently a mixture of evidence-based practices, promising practices and emerging methods that can be effectively tied together using the psychiatric rehabilitation process framework of helping individuals with serious mental illnesses choose, get and keep valued roles, and together with complementary treatment orientated psychosocial interventions, provide a broad strategy for facilitating recovery.

A review of PR interventions must therefore take into account the aim of psychiatric rehabilitation (i.e. improving role performance in a chosen environment) within the overall mission of enhancing recovery (Farkas & Anthony, 2010.)

**Process framework for psychiatric rehabilitation, person level process**

	<b>Choosing a valued role</b>	<b>Getting a valued role</b>	<b>Keeping a valued role</b>
<b>Provider Process</b>	<b>Engaging</b>	<b>Linking with existing worker/worker/student/residential/social role opportunities</b>	<b>Assessing critical skill and/or support strengths and deficits</b>
	<b>Assessing and developing readiness</b>	<b>Creating worker/worker/student/residential/social role opportunities</b>	<b>Person-centered planning</b>
	<b>Setting an overall goal</b>		<b>Developing skills to succeed in the preferred role</b>
			<b>Developing supports to succeed in the preferred role</b>

*Source: Farkas & Anthony, 2010*

The process is designed to help people decide on the goals they wish to achieve, help them identify what skills they have and what skills they need to learn, and identify the resources or supports they already have and those they need to develop in order to achieve their goals. The next steps are to help them develop the skills and resources they need (Anthony & Farkas, 2009). This process is one that has been incorporated into many aspects of service delivery. For example, people receiving medical and mental health pharmacotherapy often are taught medication use; individuals who receive case management services are given support to access the services they need and people who receive supported employment learn skills to succeed vocationally.

The model is built on the premise that recovery and rehabilitation efforts have two foci: facilitating success and satisfaction in the performance of personally preferred and valued roles, and creating or promoting an increase in opportunities for participation in society. This is accomplished by assisting individuals to achieve their full functional capacity. For some individuals with serious mental illness, this means reduced inpatient stays, while for others it may mean a return to educational training, employment or a more satisfying personal life. Helping people with serious mental illness achieve their goals is accomplished by ensuring that the person has the skills and supports necessary for success and satisfaction and is a basic principle of PSR (Anthony, Cohen, Farkas & Gagne, 2002; Farkas, Jansen & Penk, 2007).

Recently, Bennett Cattaneo and Chapman (2010) highlighted the importance of learning skills and the link to increased self efficacy and action to practice the skill. Success in taking such action can further refine skills and promote increased self-efficacy, leading to further refinement of skills, and even greater self-efficacy (Kieffer, 1984). Identification of skills available and needed for success is a critical component of the PSR process.

The model focuses on facilitating a specific practitioner and consumer process to guide the consumer to choose, get, and keep preferred societal role(s) or a rehabilitation goal(s). Practitioners develop a personal connection with consumers in order to facilitate, support or teach consumers how to:

- Assess their own readiness for change
- Set their own goal(s) in terms of the role they prefer (student, worker, tenant etc)
- Identify their own skill and resource strengths and deficits in relation to this goal
- Develop a plan
- Teach new skills, or
- Organize strategies to help the person overcome the barriers to using skills they have
- Link to existing resources, or
- Create new resources.

The components of the process are what practitioners do to facilitate rehabilitation (Farkas, Cohen & Nemec, 1988). Choosing, getting and keeping are what individuals do to achieve success and satisfaction in their preferred societal roles. Critical to the approach is an emphasis on developing practitioner competencies in engaging, supporting, and teaching people how to drive and master their own rehabilitation process, regardless of their level of functioning. Pre-experimental studies, quasi-experimental research, and two randomized controlled trials have been conducted on the approach in the domains of employment, housing, and education (Hutchinson, Anthony, Massaro & Rogers, 2007; Shern, Tsemberis, Anthony, Lovell, et al., 2000; Rogers, Anthony, Toole & Brown, 1991). Positive outcomes in the area of quality of life, housing status, work status, other role functioning, and a decrease in service utilization have been identified, among others (Hutchinson, Anthony, Massaro & Rogers, 2007; Rogers, Anthony & Farkas, 2006).

The approach can be used with the evidence based, promising practices and supporting services discussed in the other two Interventions modules, Interventions II and Interventions III.

## Challenges

Virtually all mental health practitioners, including psychologists, want to do the best they can to assist the people they work with achieve the best outcomes possible. However, far too few mental health practitioners have been trained to provide services from a recovery oriented perspective and consequently, most do not know how to translate the guiding principles of recovery into practice. Further, too few mental health service delivery systems provide integrated and coordinated services; this is needed to avoid omission of needed services, duplication of service provision, and confusion for service recipients.

## Summary

We know that recovery from serious mental illness frequently occurs. Many people with serious mental illness are able to gain or re-gain the functional capabilities needed to have a satisfying, productive, and meaningful life.

In order for the services provided to help people recover, service providers need to demonstrate several critical values and subscribe to the underlying principles that people with serious mental illness consistently describe as critical. These have been enumerated and described during two national processes that gathered input from people who themselves have experienced serious mental illness and have recovered. These guiding principles form the platform upon which PSR interventions are designed and implemented.

In order to implement PSR interventions properly, services need to be coordinated and integrated. One model that can be used to help with this is known as the Choose, Get, Keep model, which is designed to assist practitioners as they work to help consumers engage in the process, set goals for themselves, identify the skills and resources they need to achieve their desired goals, and acquire the needed skills and resources.

## Sample Learning Activity

There are two parts to this exercise. For the first part of the exercise, depending on the size of the group, participants should be divided into groups of 8 to 10 members. Do not give out the instructions for subsequent portions of the exercise until the start of that portion.

Part I - Do not tell participants that something on the list will be crossed off. On a blank sheet of paper, each person is to write down the three most important things in his or her life – the things that give meaning, keep him or her happy, the individual reasons each person gets up in the morning, etc. Only the three very most important things in each person's life are to be written down.

When each person has written the three things on his or her paper, the following instruction is to be given: Group members are to exchange the lists with the person next to each one – there should be no discussion about the lists. The person who receives the list is to cross one thing off the list without consulting with the original writer and return it.

With a consumer participant as the leader of the group, the following questions should be discussed/processed:

General – for the full (small) group:

- What kinds of things got crossed off the lists?

For each participant:

- How does it feel to imagine your life without the item that was crossed off?
- How does it make you feel that the person crossed one of the most important things in your life (e.g., your daughter/gardening/faith in God/etc.) off the list without asking for your input?

Part II: For the second part of the exercise, the large group should reconvene if participants were divided into smaller groups.

As a large group, participants should discuss each of the following:

- In traditional treatment settings, other people have the power to decide the focus of a consumer's life over the next several months or years – what makes it on the list and what doesn't?
- Some consumers are excluded completely from these decisions, others are told it is "not in their best interest," or the "timing is not right" to... go back to school/work... move out of the group home...regain custody, etc.
- Over 90% of treatment plans continue to identify the goals of clinical stability/med-compliance/and abstinence as the only priorities -- to the exclusion of other life domains that are critical elements of anyone's sense of well being.

- Whenever clinicians work with people, it is helpful to remember this exercise and how it feels to have something important to you crossed off your list because someone said it was not a priority or said you needed to wait until you were ready, etc.
- Now imagine what your attitude and response to this kind of treatment would be if this were not just an exercise. What if this happened to you?

## Sample Evaluation Questions

### Question

### Correct Answer

1. The following are some of the guiding principles identified as important for recovery:

- a) Sense of hope
- b) Empowerment and self direction
- c) Assistance from support networks
- d) Avoidance of stress, especially discussions of past trauma
- e) all of the above
- f) a and c only
- g) a, b, and c

g) is the correct answer

2. Which of the following are part of the process of delivering psychosocial rehabilitation?

- a) Assisting people to set goals for themselves
- b) Identifying skills that the person possesses and those that are needed to achieve the desired goal(s)
- c) Providing services that the person served agrees are best suited to helping him or her achieve the desired goal(s)
- d) b and c
- e) all of the above

e) is the correct answer

True

False

3) When a person's symptoms flare up and he or she is having difficulty making decisions, an advance directive should be prepared by the family to ensure that the person receives the most appropriate treatment

X

4. Recovery from serious mental illness will be facilitated by professionals who are familiar with the literature and make decisions based on the research about interventions each person should receive

X

5. Research has shown that prior to beginning the PSR process, people with serious mental illness should be psychiatrically stable, i.e., they should not be experiencing any symptoms so they can participate fully

X



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## **Additional Resources**

American Psychological Association Recovery to Practice Initiative.

<http://www.apa.org/pi/rtp>

Boston University Center for Psychiatric Rehabilitation. (2000–2010). *Training Curricula*. Boston, MA: Boston University, Center for Psychiatric Rehabilitation.

## Citing the Curriculum

Citation for this Module:

American Psychological Association & Jansen, M. A. (2014). Interventions I: Guiding Principles and Integrated Framework. *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association, Recovery to Practice Initiative.

Citation for the full Curriculum:

American Psychological Association & Jansen, M. A. (2014). *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

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# American Psychological Association

## Recovery to Practice Initiative Curriculum: Reframing Psychology for the Emerging Health Care Environment

### *8. Interventions II: Evidence Based Practices*

**NOTE:** There are three Interventions modules. They are designed to be used together and are not intended to be used separately or as stand alone modules

August 2014

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## Overview

This is the second of three modules on Interventions. The three modules are designed to be used together; they cannot stand alone as the content of any one is not sufficient to understand or provide Psychosocial Rehabilitation (PSR) interventions.

In Interventions I, the guiding principles that underlie the provision of all PSR services are discussed along with an integrative framework model that can be used to coordinate PSR services. The guiding principles are essential for the successful implementation of the interventions discussed in Interventions II and Interventions III. In Interventions II, interventions that have been proven through empirical research to achieve specific outcomes are presented; these are known as evidence based practices (EBPs). In Interventions III, interventions that have shown promise of achieving specified outcomes are presented; these are known as promising or emerging practices. Interventions III also presents supporting services that are widely acknowledged to be essential services for helping people recover from the effects of serious mental illness.

Importantly, research evidence has been accumulating that an integrated approach that combines multiple interventions within a recovery oriented context may be the most effective approach (Lyman, Kurtz, Farkas, George, Dougherty, et al., 2014; Spaulding & Deogun, 2011) and scholars are increasingly calling for such an integrated, recovery oriented system (Davidson & Chan, 2014). Such an approach must be targeted to the unique needs of each individual including those in forensic and criminal justice systems (Epperson, Wolff, Morgan, Fisher, Frueh & Huening, 2011; Strauss, 2014). In addition, it has become apparent that cognitive impairment is likely at the heart of the functional skill deficits so commonly experienced by people with serious mental illnesses (Harvey & Penn, 2010) leading to the conclusion that integrated approaches should include cognitive enhancement approaches as a fundamental component (Pfammatter, Brenner, Junghan & Tschacher, 2011; Roder, Mueller & Schmidt, 2011) and underscores the importance of social cognition for improving community functioning. Indeed, some have stated that including cognitive remediation “may result in a magnitude of change that exceeds that which can be achieved by targeted treatments alone” (Pinkham & Harvey, 2013, p. 499).

Notwithstanding the above, each of the EBPs, promising practices, and supporting services are discussed separately in the interventions modules (Interventions II and Interventions III) because as of the publication date of this curriculum, no definitive combination of approaches has been determined to be most effective, although some combination of cognitive therapies (cognitive remediation, social cognition training, cognitive behavioral therapy), supported employment, psychoeducation (client/family approaches, illness management approaches), and social and communication skills training, seems to be most promising. As the research literature evolves, additional interventions, especially those that contain a cognitive or learning component, may be identified as critically important. Furthermore, identification of which interventions work best for whom, under which

conditions, at which stage of illness, and potentially at which age of each individual, may lead to the development of personalized approaches tailored for each individual.

## Learning Objectives

At the end of this module you will be able to:

- State at least three reasons why the PORT recommendations are important for the design of mental health service systems
- Identify at least four evidence based PSR services
- Identify at least three key characteristics for each of the identified EBPs
- Identify and discuss at least three conditions important for ensuring success when providing evidence based and other services derived from research
- Describe at least two reasons why psychologists and other practitioners might be resistant to implementing EBPs

## Resources

- Lecture Notes
- Required Readings
- Lecture Notes Citations
- Sample Learning Activity
- Sample Evaluation Questions
- Additional Resources

## Required Readings

Davidson, L. (2010). PORT through a recovery lens. *Schizophrenia Bulletin*, 36, 1, 107–108.

Dixon, L. B., Dickerson, F., Bellack, A. S., Bennett, M., et al. (2010). The 2009 schizophrenia PORT psychosocial treatment recommendations and summary statements. *Schizophrenia Bulletin*, 36, 1, 48-70.

Kreyenbuhl, J., Buchanan, R.W., Dickerson, F. B. & Dixon, L. B. (2010). The Schizophrenia Patient Outcomes Research Team (PORT): Updated treatment recommendations 2009. *Schizophrenia Bulletin*, 36, 1, 94-103.

## Activities

Complete the following activities:

- Read the lecture notes

- Read the required readings
- Engage in a learning activity related to this module
- Evaluate students' understanding of this module.

## Lecture Notes

People with lived experience of serious mental illness are strongly encouraged to be part of the delivery of the curriculum including being active participants in the delivery of the lecture. Refer to the curriculum Instruction module for additional information.

### Introduction

As described in previous modules, studies over the past several decades have shown that many adults with serious mental illnesses can and do recover when they are provided with supports and services that assist them to gain the skills needed to live a satisfying and productive life. Users of mental health services have consistently said that they want the same things for themselves that every citizen wants: a family, a safe place to live, meaningful activities, adequate income, job satisfaction, and an enjoyable social life. Where children and youth are concerned, the same is true: families seeking services for children with mental health concerns want services that promote the development of competencies, and functional lifetime outcomes (Bellonci, Jordan, Massey, Lieberman, Zubritsky & Edwall, 2012).

For people with serious mental illnesses, attainment of life goals often requires substantial assistance in the form of specially designed psychosocial rehabilitation (PSR) services. While some people with serious mental illness may recover without assistance, many are unable to recover sufficiently to achieve the quality of life that they desire without these specialized services (Silverstein, 2000). Several of these specialized services have been shown in multiple randomized clinical trials to be highly effective; these are known as evidence based practices (EBPs).

It is important to keep in mind that none of the interventions are suggested as a “cure” for serious mental illness. Rather these interventions are a means to inform individuals and their families about the illness and to help individuals achieve the life goals they have for themselves. It is also important to keep in mind that all interventions must be provided within a recovery oriented framework and perspective that is person centered, draws on the strengths and capabilities of the individual, and is oriented to the goals of the person served (Davidson, 2010; Mueser, 2012).

### Evidence Based Practices (EBPs)

As discussed in the first module in the Interventions series, we know that services must be guided by the following:

- Recognition that recovery and return to a satisfying and productive life are possible;
- Provision of interventions that are grounded in research and achieve results;

- Acceptance that, to the greatest extent possible, those with serious mental illnesses and their families are full partners with the service delivery system and determine the services they will receive.

With this as a foundation, we will now discuss the evidence that supports provision of skills building interventions.

The evidence base supporting use of PSR services for people with serious mental health disorders has developed considerably over the past two decades and is now quite robust. Provision of EBPs, promising practices, and supporting services within an integrated PSR model has been shown to improve the functional capability of individuals with serious mental illnesses and improve outcomes across a broad spectrum of domains when compared with standard care (Patterson & Leeuwenkamp, 2008).

In order for individuals with serious mental illnesses to achieve improved outcomes, a range of clinical interventions is often necessary, ranging from pharmacologic to psychosocial<sup>1</sup>. The recommendations of the Schizophrenia Patient Outcomes Research Team (PORT) are now considered to be the gold standard for guiding mental health treatment for people with serious mental illness. Because of the relevance of the PORT recommendations to this module on Interventions, the following is abstracted from the first update of the PORT study (Lehman, Kreyenbuhl, Buchanan, et al., 2004), and from the most recent update (Kreyenbuhl, Buchanan, Dickerson & Dixon, 2010) of the PORT recommendations:

Since publication of the original Schizophrenia Patient Outcomes Research Team (PORT) treatment recommendations in 1998, considerable scientific advances have occurred in our knowledge about how to help persons with schizophrenia. Today an even stronger body of research supports the scientific basis of treatment. This evidence, taken in its entirety, points to the value of treatment approaches combining medications with psychosocial treatments, including psychological interventions, family interventions, supported employment, assertive community treatment, and skills training. The most significant advances lie in the increased options for pharmacotherapy, with the introduction of second generation antipsychotic medications, and the greater confidence and specificity in the application of psychosocial interventions. Currently available treatment technologies, when appropriately applied and accessible, should provide most patients with significant relief from psychotic symptoms and improved

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<sup>1</sup> The literature base is well developed for those with psychotic disorders, especially schizophrenia and schizoaffective disorders, but less well developed for bi-polar disorder, clinical depression, personality disorders, and concurrent addictive disorders. While some studies exist, most researchers have assumed that the findings from major studies of individuals with schizophrenia would generalize to others with serious mental illnesses. Due to the paucity of research specific to these disorders, this document likewise assumes to generalize the findings to these populations as well.

opportunities to lead more fulfilling lives in the community (Lehman, Kreyenbuhl, Buchanan, et al., 2004, p. 193).

This latest update of the PORT recommendations has identified 24 treatment areas that have strong empirical evidence for improving outcomes and which should comprise the basic menu of treatments and services available to all people with schizophrenia. Consistent with the paradigm shift in schizophrenia treatment from a focus on long term disability to one focused on optimism and recovery, the ultimate goal of the Schizophrenia PORT has been to increase the use of evidence based treatments in order to optimize outcomes by reducing illness symptoms and the disability and burden associated with the illness (Kreyenbuhl, Buchanan, Dickerson & Dixon, 2010, p. 100).

Of the 24 treatment recommendations in the updated PORT, 16 relate to pharmacologic treatments and 8 relate to PSR interventions. The 8 PSR interventions are:

...assertive community treatment, supported employment, cognitive behavioral therapy, family-based services, token economy, skills training, psychosocial interventions for alcohol and substance use disorders, and psychosocial interventions for weight management. Reviews of treatments focused on medication adherence, cognitive remediation, psychosocial treatments for recent onset schizophrenia, and peer support and peer-delivered services indicated that none of these treatment areas yet have enough evidence to merit a treatment recommendation, though each is an emerging area of interest (Kreyenbuhl, Buchanan, Dickerson & Dixon, 2010, p. 48).

The following sections of this module discuss the 8 EBPs. The third Interventions module discusses the 4 promising interventions mentioned above and also provides information about services that are highly supportive for people with serious mental illness. Many of the interventions are often combined and frequently overlap, thereby providing reinforcement of the components. Most of the interventions target functions that are needed for success in many areas of life. Despite this broad applicability, the interventions were primarily developed with a particular focus in mind and their effectiveness has been determined based on meeting that particular focus or goal.

### **Assertive Community Treatment**

The most well known and researched evidence based practice is assertive community treatment (ACT). Originally developed and researched in the late 1970s (Stein & Test, 1980), ACT has become the cornerstone around which community mental health treatment for those with the most serious mental illness is provided (Dixon, 2000).

Those who receive services from an ACT program are typically those that have not benefited from traditional approaches to providing treatment, although recently the model has been implemented with those experiencing a first episode of psychosis (FEP). Provision

of the ACT model with individuals with FEP resulted in the formation of greater social networks which may lead to improved clinical outcomes as a result of establishing or maintaining relationships with family and friends (Tempier, Balbuena, Garety & Craig, 2012).

ACT is designed to help people overcome the challenges they face including difficulties with basic, everyday activities such as developing and maintaining relationships, caring for their basic physical needs, maintaining safe and adequate housing, unemployment, substance abuse, homelessness, and involvement in the criminal justice system. Services are provided by a multidisciplinary team that should have enough staff so that there is a comprehensive mixture of expertise and sufficient coverage for the hours of operation. At the same time, to operate as a team, the team must be small enough to communicate easily and allow all members to be familiar enough with each consumer's status so that they can step in to provide care at any time. A team of 10 to 12 members with a total caseload of 100 persons is suggested, although teams serving a large number of individuals with acute needs may find that a smaller caseload is needed until the individuals stabilize. The types of services that are provided and how long those services are provided depend on people's needs. The team meets each day to discuss how each person is doing and services are adjusted quickly when necessary. When people need more support, team members meet with them more frequently. Staff respond to people in the community 24 hours a day, 7 days a week. As people improve, the team decreases their interactions with them, but team members remain available to provide additional support any time it is needed.

The model has been tested in countries all over the world and the results have been sustained (Marshall & Lockwood, 1998). ACT is now considered the standard for case management services for those with the most serious mental illnesses (Bond, Drake, Mueser & Latimer, 2001; Burns, Fioritti, Holloway, Malm, et al., 2001; Burns & Santos, 1995; Phillips, Burns, Edgar, Mueser, et al., 2001), and after 30 years, the principles of this model remain the same. ACT teams have not always included psychologists and the reason for this is not clear. Psychologists have much to contribute to interdisciplinary efforts such as ACT teams where varied psychological expertise can make substantial contributions to this highly effective intervention. A toolkit for implementing ACT can be found at <http://store.samhsa.gov/facet/Professional-Research-Topics/term/Evidence-Based-Practices>.

### **Supported Employment**

Along with assertive community treatment, supported employment (SE) is one of the most researched and validated interventions available. The most widely implemented version of supported employment is known as individual placement and support (IPS) and this term has become practically synonymous with supported employment, although the EBP is known as supported employment.

Strong outcome data exist to support the efficacy of this EBP for persons with serious mental illnesses (Becker, Whitley, Bailey & Drake, 2007; Bond, Drake, Mueser, et al., 1997).

Supported employment is a place and train model which uses the principle of on the job training as its cornerstone. This means that individuals with mental health disorders learn how to find and keep regular, real world jobs in the community and are provided with continuous support to assist them to achieve success. Outcomes for supported employment have been shown to be much better than for traditional approaches and this finding has been replicated in several countries (Burns, Catty, Becker, Drake, et al., 2007; Catty, Lissouba, White, et al., 2008; Corbiere, Lanctot, Lecomte, Latimer, et al., 2010; Harry, van Busschbach, Stant, van Vugt, Weeghel & Kroon, 2014; Heffernan & Pilkington, 2011; Hoffmann, Jäckel, Glauser & Kupper, 2012; van Erp, Femke, Giesen, van Weeghel, et al., 2007; Wong, Chiu, Tang, Mak, et al., 2008).

One of the most comprehensive reviews of the research was a Cochrane review completed in 2001. This review of eighteen randomized controlled trials found that supported employment was superior to programs that offered pre-vocational training (Crowther, Marshall, Bond & Huxley, 2001). A more recent review of twelve systematic reviews and seventeen randomized controlled trials of the individual placement and support model of supported employment also found consistently positive results (Marshall, Goldberg, Braude, Dougherty, Daniels, et al., 2014). As a result, the model is now recommended as the intervention of choice for those who want to work.

Programs that have implemented evidence-based supported employment find that fewer crises occur because individuals are focused on using their strengths, developing their lives in the community, and managing their illness more independently, which leads to enhanced self esteem and sense of self worth. The comprehensive and coordinated planning that occurs with supported employment leads to fewer crises, less chaos, and more structure, and the on-going support of the employment specialist, whose caseload is generally no more than 25 individuals, provides the help often needed to sustain employment (Bond, Becker, Drake, et al., 2001; Burns, Catty, White, Becker, et al., 2009).

Additionally, research has found that when supported employment is combined with other mental health services in a highly integrated model of service delivery, employment rates for those with serious mental illness can be more than double that of those who receive supported employment without additional services and individuals achieve significantly higher earnings and remain employed for longer periods (Cook, Lehman, Drake, et al., 2005; Cook, Leff, Blyler, et al., 2005). Cognitive remediation has recently been paired with supported employment in several studies and found to enhance the effects of supported employment (Bell, Choi, Dyer & Wexler, 2014; Lindenmayer, McGurk, Mueser, Kahn, et al., 2008; McGurk, Mueser & Pascaris, 2005).

The essential principles of supported employment are:

- Focus on competitive employment
- Rapid job searches
- Jobs tailored to individuals



- Time-unlimited follow-along supports
- Integration of supported employment and mental health services
- Zero exclusion criteria (that is, no one is screened out because they are not thought to be ready).

A toolkit for implementing supported employment can be found at <http://store.samhsa.gov/facet/Professional-Research-Topics/term/Evidence-Based-Practices>.

One issue that remains to be resolved for any work program is the effect that added income can have on disability payments. Thus, although supported employment can assist an individual to become successful in the work environment, the individual may choose to not work or to work for a limited number of hours in order to avoid risking loss of disability and other benefits.

### **Cognitive Behavioral Therapy**

Cognitive Behavioral Therapy (CBT) is a form of psychotherapy that uses education and behavioral shaping techniques to help individuals learn to think more rationally, and learn to act differently based on this more rational thinking. It is a combination of cognitive therapy which teaches rational thinking skills, and behavioral therapy which teaches behavioral skills. There can be a range of therapeutic approaches that are included under the rubric of CBT. CBT is not aimed specifically at eliminating symptomatology, i.e., changing either positive or negative symptoms, although the severity of these may be reduced. Rather it is aimed at helping those with serious mental illness learn to manage their illness better by learning to challenge their irrational thoughts and act differently. Thus, rather than “making the demons go away”, it can be thought of as learning to “manage the demons”. Medication may provide a useful assist in the management of symptomatology.

CBT is considered to be an integral component of most mental health treatment systems and is present in many mental health treatment systems around the world. Much research has supported its efficacy (Butler, Chapman, Forman & Beck, 2006; Cather, Penn, Otto, et al., 2005; Dickerson, 2000; Dickerson & Lehman, 2006; Garety, Fowler & Kuipers, 2000; Gould, Mueser, Bolton, et al., 2001; Granholm, Loh, Link & Jeste, 2010; Haddock, Barrowclough, Tarrier, et al., 2003; Kavanagh & Mueser, 2001; Pfammatter, Junghan & Brenner, 2006; Scott, 2001; Wykes, Steel, Everitt & Tarrier, 2008).

#### *Specialized CBT for Psychosis*

Recently, specialized applications of CBT for psychosis (CBTp) have also been developed and tested, with positive results (Lecomte, Leclerc, Corbiere, Wykes, Wallace & Spidel, 2008; Morrison & Barrett, 2010; Rector & Beck, 2001; Wykes, Steel & Tarrier, 2008; Zimmerman, Favrod, Trieu & Pomini, 2005). Research is currently underway to determine the effect of CBTp for individuals experiencing recent onset psychosis and those considered in the prodrome phase or at ultra high-risk of developing psychosis.

CBTp treatment is aimed at psychotic symptoms but treatment also targets anxiety, low mood, self-esteem, etc. There is strong emphasis on development of the therapeutic alliance focused on understanding the client's experience of psychosis in order to normalize this experience and facilitate willingness to discuss symptoms, experiences, and impact of the experience on functioning. Treatment can be provided individually or in a group setting (Mueser, Deavers, Penn & Cassisi, 2013). Client engagement, recognition of possible cognitive deficits, acceptance of suspiciousness that might arise and willingness to be flexible are key (Morrison & Barrett, 2010; Mueser, Deavers, Penn & Cassisi, 2013).

A recent meta-analysis reinforced the previously found positive outcomes for CBTp, finding that CBTp was more effective for reducing positive symptoms, while social skills training was more effective for reducing negative symptoms (Turner, van der Gaag, Karyotaki & Cuijpers, 2014).

### **Family Based Services (also known as Family Psychoeducation)**

Along with assertive community treatment and supported education, family psychoeducation is one of the most researched and validated interventions. Family based services or family psychoeducation, is the process of providing education and coping skills for people with lived experience of serious mental illnesses and their families. Family psychoeducation is generally provided in multi-family groups but can also be offered in single family formats. Multi-family formats have the added benefit of allowing for the development of social support systems. Consent of the individual with the illness is always required. Information about the person's illness is provided along with information for both consumer and family about recognizing the onset of symptoms, coping with behavioral changes, effects of medication, and communication skills. Family psychoeducation is a treatment modality that utilizes the consumer and family as partners in the provision of the service, not as objects of the treatment modality and whose primary focus is on the needs and desires of the consumer (Miklowitz, George, Richards, Simoneau, et al., 2003).

The effectiveness of family psychoeducation has consistently been documented. Studies undertaken in several different countries over the past two decades have shown remarkable success in reducing rates of relapse (Dixon, McFarlane, Lefley, Lucksted, et al., 2001; Fristad, Goldberg-Arnold & Gavazzi, 2002; Glynn, Cohen, Dixon & Niv, 2006; Miklowitz, George, Richards, Simoneau, et al., 2003; Miklowitz & Goldstein, 1997; Miklowitz, Simoneau, George, Richards, et al., 2000; Mueser & Glynn, 2000; Pfammatter, Junghan & Brenner, 2006; Sikich, 2005).

A recent review of over thirty randomized controlled trials of psychoeducation for individuals with serious mental illnesses and over one hundred randomized controlled trials of family psychoeducation provides a high level of evidence for the effectiveness of the model. The authors state:

Reviews of consumer psychoeducation found that experimental groups had reduced nonadherence (primarily with medication regimens), fewer relapses, and reduced hospitalization rates compared with control groups. Some studies found significant improvements in social and global functioning, consumer satisfaction, and quality of life. Multifamily psychoeducation groups (the focus of numerous studies) were associated with significantly improved problem-solving ability and a reduced burden on families, compared with control groups, among other strong outcome effects. ... Psychoeducation should be included in covered services. Group and family interventions are especially powerful (Lyman, Braude, George, Dougherty, Daniels, et al., 2014).

Additionally, on average, rates of re-hospitalization have been consistently shown to be reduced by an average of 50 percent, with the range between 40 and 70 percent (Dixon, Adams & Lucksted, 2001; Pitschel-Walz, Leucht, Bauml, Kissling, et al., 2001). Rates of employment are also significantly higher among those who have participated in family psychoeducation. Other findings include improved family member well-being, decreases in negative symptoms, and decreased costs of general medical care (Campbell, 2004).

There are several essential elements of family psychoeducation programs including:

- Developing the relationship
- Educational workshops
- Skills building for community re-entry
- Social and vocational skills development.

The most effective family psychoeducation programs are six to nine months in duration and the best effects are shown for programs that continue for longer durations (Pitschel-Walz, Leucht, Bauml, Kissling & Engel, 2001). This is also the case for family interventions designed for clients and families where concurrent substance abuse is present (Mueser, Glynn, Cather, Xie, et al., 2013). Due to the difficulty of maintaining families in programs of long duration, current research is focusing on determining the efficacy of shorter duration programs and some have begun to demonstrate success in helping families feel empowered and better able to cope, and have lessened anxiety and depression (Dixon, Lucksted, Medoff, Burland, et al., 2011). Recently, brief interventions consisting of fewer sessions for individuals and for family members have led to marked increases in family participation, reduced symptomatology and enhanced recovery at follow up (Dixon, Glynn, Cohen, Drapalski, Medoff, et al., 2014). A toolkit for implementing traditional Family Psychoeducation can be found at <http://store.samhsa.gov/facet/Professional-Research-Topics/term/Evidence-Based-Practices>.

### **Token Economy Interventions**

Token economies are interventions that are appropriate for long term care or residential settings where individuals with the most severe illnesses live and where improvements in

behaviors related to daily living skills are needed. In many cases individuals who would otherwise have remained hospitalized, have been enabled to live in the community as a result of the token economy intervention. Token economy interventions are long term interventions and commitment to long term, high intensity staff training and to providing the intervention over a long period of time are required.

A token economy intervention is based on social learning principles where intermediate (something that can be redeemed later such as a token) positive reinforcement is provided contingent on performance of an identified behavior. Punishment is **never** part of a token economy system and to avoid the mis-use of token economy interventions, absolute fidelity to the model is necessary. Fidelity to the EBP includes a substantial investment in staff training prior to initiation of the program and careful and sustained supervision of all staff throughout the full duration of the intervention (Silverstein, Hatashita-Wong, Wilkniss, et al., 2006).

Token economies are based on the seminal work of Paul and Lentz (1977) whose work provided the cornerstone of empirical support for social learning programs. Token economies, or social learning programs are the only interventions among the eight designated EBPs specifically recommended for long-term inpatient or residential care to improve personal hygiene, social interactions, and other adaptive behaviors.

Token economies have been used successfully in institutional settings for several decades and there are many studies that support the efficacy of this highly effective intervention (Ayllon & Azrin, 1965; Beck, Menditto, Baldwin, Angelone & Maddox, 1991; Dickerson, Tenhula & Green-Paden, 2005; Glynn, 1990; Hall, Baker & Hutchinson, 1977; Silverstein, Hatashita-Wong, Wilkniss, et al., 2006).

### **Skills Training**

Skills training encompasses a broad range of training in skills needed for functioning in everyday life including basic communication, assertiveness training, training in skills associated with a variety of social and vocational settings, and skills needed for personal care, independent living and community integration. Skills training, often named social skills training, is applicable not only to social skills, but to any area of life where concentrated practice of a new skill can assist functioning in areas such as obtaining further education or learning to be successful in a work setting. Skills training is not aimed at reducing symptoms but rather at helping people live with their illness and its symptoms in a more functionally adaptive way and has been shown to be highly effective for helping individuals learn specific skills or skill sets (Bellack, 2004; Bustillo, Lauriello, Horan & Keith, 2001; Kopelwicz, Liberman & Zarate, 2007; Kurtz & Mueser, 2008; Penn & Mueser, 1996).

Skills training derives from the behavioral literature and consists of instructional teaching techniques and behavior shaping techniques. Instructional teaching techniques involve didactic instruction, modeling, and experiential practice with feedback until the skill is

understood and in the control of the individual. Behavior shaping involves systematic practice and reinforcement of the desired behavior until the criteria are met.

Skills training is often essential for success in community living and can encompass training in skills such as negotiating a place to live, making friends, using public transportation, and other everyday situations. Skills training can be especially helpful for situations where interaction with others is either necessary or beneficial.

An important factor is that the skills learned have not always generalized to everyday living situations and have not always been sustained. Interventions designed to reinforce the learned achievements and to provide support for maintenance have shown enhanced levels of interpersonal problem - solving skills, significantly greater social adjustment and better quality of life. Results have been shown to be sustained for several months to more than two years (Glynn, Marder, Liberman, Blair, et al., 2002; Liberman, Glynn, Blair, Ross, et al., 2002; Pfammatter, Junghan & Brenner, 2006; Tauber, Wallace & Lecomte, 2000). Thus, support for maintenance of learned behaviors and skills should be built into service delivery systems to ensure sustainability.

Like CBT, virtually all mental health systems utilize skills training to assist individuals with a wide range of disorders to learn skills that will help them function more successfully in a broad array of situations.

### **Psychosocial Interventions for Alcohol and Substance Use Disorders (also known as Concurrent Disorders Treatment or Integrated Dual Diagnosis Treatment)**

People with serious mental illnesses often have co-occurring substance use disorders; prevalence rates of co-morbidity range between 13 – 45% for those in contact with mental health services living in the community (Rush & Koegl, 2008). Estimates for the prevalence of concurrent substance use and mental health disorders overall range from 27 percent to more than 60 percent. Most literature reviews note that the prevalence of concurrent disorders in North America is quite high (Health Canada, 2002; Margolese, Malchy, Negrete, et al., 2004; National Alliance for the Mentally Ill, 2005; Watkins, Hunter, Wenzel, et al., 2004). Use of psychoactive substances exacerbates the symptoms of mental illness and can impede treatment. Treatment for those with concurrent disorders is most effective when the treatment for both disorders is integrated and offered by one provider or one team with knowledge of both disorders. This is to ensure that the individual receives a consistent explanation of illness/problems and a coherent treatment plan rather than a contradictory set of messages from different providers.

It is generally agreed that the key elements of integrated dual diagnosis treatment are:

- Assertive outreach
- Integrated case management
- An individualized treatment plan that addresses both the substance use disorder and the person's mental illness

- Integrated services provided by the same clinician or clinical team
- Availability of multiple therapeutic approaches
- Comprehensive approach
- Knowledge about the effects of alcohol and drugs and their interactions with mental illness and the medications that are used to treat mental illnesses
- Reduction of negative consequences
- Cognitive behavioral therapy
- Stage-wise treatment provided as individuals progress over time through different stages of recovery
- Relapse prevention
- Motivational interviewing to help the individual develop awareness, hopefulness, and motivation
- Long term approach to ensure time unlimited treatment (Drake, Mercer-McFadden, McHugo & Bond, 1998; Haddock, Barrowclough, Tarrier, et al., 2003; Mueser, Noordsy, Drake & Fox, 2003).

Lack of attention to any of the elements can jeopardize the effectiveness of the treatment program. Shared decision making which includes the client and his or her family, is at the core of integrated treatment and is critical to success (Mueser, Noordsy, Drake & Fox, 2003).

Recent research also found enhanced outcomes when family interventions including communication and problem solving training, were combined with treatment for the substance use disorder. This research identified that persons with serious mental illness receiving the combined intervention had improved functioning and significantly less severe overall psychotic symptoms and their family members also had improved mental health functioning and greater knowledge of co-occurring disorders (Mueser, Glynn, Cather, Xie, et al., 2013).

A toolkit for implementing treatment for concurrent disorders can be found at <http://store.samhsa.gov/facet/Professional-Research-Topics/term/Evidence-Based-Practices>.

### **Psychosocial Interventions for Weight Management**

Interest in designing and researching interventions aimed at helping individuals manage their weight is relatively recent. Much of this interest can be attributed to the fact that most of the second generation anti-psychotic medications cause substantial weight gain for many individuals, which can lead to other serious health problems; the combination of these health problems is known as the metabolic syndrome. Metabolic syndrome is much more prevalent in people using anti-psychotic medications and can lead to diabetes and an increased risk of cardiovascular events such as heart attack and stroke. A recent meta-analysis of the literature found that the prevalence of metabolic syndrome in people with

schizophrenia and related disorders is consistent across treatment setting (inpatient vs outpatient), country of origin, and gender. Older individuals were at greater risk and those who had been ill the longest had the highest risk of developing the syndrome. When individual studies were evaluated, waist size was most useful in predicting metabolic syndrome and use of antipsychotic medication, especially clozapine, conveyed the highest risk. Those who did not use anti-psychotic medications were at lowest risk of this life threatening syndrome (Mitchell, Vancampfort, Sweers, van Winkel, Yu & de Hert, 2013).

Several randomized clinical trials of PSR interventions designed to help individuals lose weight have demonstrated substantial improvement for the PSR intervention compared to control or non PSR conditions (Brar, Ganguli, Pandina, Turkoz, et al., 2005; Jean-Baptiste, Tek, Liskov, et al., 2007; Kwon, Choi, Bahk, et al., 2006; Weber & Wyne, 2006; Wu, Wang, Bai, et al., 2007; Wu, Zhao, Jin, et al., 2008). Additionally, there have been several studies of individuals who had just begun to take anti-psychotic medications and these have also shown significant differences in the amount of weight gained by people beginning treatment (Álvarez -Jimenez, Hetrick, Gonzalez-Branch, et al., 2008; Evans, Newton & Higgins, 2005; Littrell, Hilligoss, Kirshner, et al., 2003). The effects can be difficult to maintain however and booster sessions and or continuation of the weight management intervention may be needed (Álvarez-Jiménez, Martínez-García, Pérez-Iglesias, Ramírez, et al., 2010). Because of the weight inducing effects of anti-psychotic medications, losing weight once it has been gained can be very difficult for individuals taking these medications; it is thus important to begin weight management intervention at the earliest possible time.

Recent research has identified that pharmacologic interventions may be helpful in preventing or reducing weight gain associated with anti-psychotic medications (Mahmood, Booker, Huang & Coleman, 2013). Because of the serious health implications associated with obesity, and the great difficulty that people with serious mental illnesses who are using antipsychotic medications have in controlling their weight, individuals should be monitored very closely for early signs of respiratory and cardiovascular disorders, for cancers of all kinds, and provided with the newest and best pharmacologic interventions available.

Due to the potentially life saving benefits of managing one's weight, interventions for weight management should be an essential component of the PSR continuum of services offered. An important but unaddressed issue concerns the management of diabetes that often develops in individuals especially when weight gain is rapid. Interventions to prevent the onset of diabetes and manage those cases that do develop, need to be designed and tested so they can be integrated into weight management programs to assist in the prevention and control of this potentially life threatening disease.

## **Important Considerations for Implementation of Services Designated as Evidence Based Practices and Services with Outcomes Derived from Research**

There are several important considerations to note when EBPs are to be implemented. Success of the interventions depends on adhering to these principles.

### **Fidelity to the Researched Model**

Many agencies and organizations attempt to provide only certain components of an EBP and this generally fails to produce the intended result. EBPs must be provided as they were developed and researched, i.e., provided with fidelity to the practice as described in the literature. Simply calling a service by the name of an EBP, or offering parts of the practice, or modifying it to shorten it or save money defeats the essential purpose of EBPs. The factor that makes them evidence based is that a certain intervention, provided in a certain way, was found to be effective. If that intervention is changed or provided in a different way, there is no evidence to suggest that it will have the desired effect (Latimer, 2010).

In addition to ensuring that the EBP is provided so that it will be effective, there is another reason that avoiding failure is important. If an intervention is called by the name of an EBP and it is suggested to administrators, funding sources, and consumers as a service that will achieve certain outcomes, but does not, all are disappointed and will likely feel misled. Moreover, it is highly likely that funding for that and possibly other services will be withdrawn and consumers and their families will no longer trust the system or agree to take part in services that promise to achieve results. If an EBP is to be offered, it is important to offer it with fidelity to the researched model and to be honest about desired and potential effectiveness.

### **Appropriately Trained and Experienced Staff**

Provision of EBPs requires that staff are fully trained and competent to implement the service as designed. Most often this means that staff must receive additional training and become experienced in the provision of the practice. Some of the EBPs require certain clinical skill sets in order to be provided appropriately. Without the proper knowledge and expertise, the intervention will likely not be provided as it was intended to be and could be harmful to service users.

Although many clinicians are trained to provide some components of most if not all of the EBPs, few are trained in every aspect of each of them. Like fidelity to the researched model, adequate training in all aspects of the practice is essential if the interventions are to be effective in assisting those with serious mental illnesses to attain recovery and reach the goals they set for themselves. This points to the need to hire appropriately trained professional staff and to thoroughly re-train existing staff and provide continuing education on a regular basis so that all practitioners can provide the interventions correctly.



Adequate, on-going supervision by practitioners who themselves are fully trained is essential (Anthony, 2008; Liberman, Hilty, Drake & Tsang, 2001).

### **Integrated and Coordinated Services Tailored to the Needs and Wishes of Each Individual**

All services, including EBPs, must be offered and provided as part of an integrated and coordinated set of services. Together with the individual, a comprehensive range of services that meets his or her needs and wishes should be decided upon. Simply offering a few services that are not driven by the needs and desires of each individual will benefit no one. And providing them without coordination of the full range of providers and supports available to the person will result in confusion, mixed messages, and possibly failure of any or all of the services. Unfortunately, providing services in a chaotic manner that lacks integration is often the case due to a variety of factors including competition among service providers, professional misunderstandings, and limited resources.

### **Challenges**

Despite the considerable advances in our knowledge of what can be helpful to people with serious mental illness, there is much that remains unknown. For example, while we have a range of EBPs that have been shown to be effective in helping people with serious mental illness achieve certain specified outcomes, we know very little about a multitude of factors that can, and often do, impact on the successful provision of these services.

Additionally, there is often resistance from psychologists and other providers who are reluctant to accept new services or instructions to change existing services. This is sometimes called evidence based pushback and can refer to resistance to accepting research findings and resistance to change. This is not unique to psychology; many practitioners who have been trained in a particular modality or who have been providing services for some time believe that they and their colleagues have offered the best there is. Suggestions to change can be taken as an insult to their best efforts to help the individuals they may have been truly dedicated to serving.

Provision of EBPs with fidelity using adequately trained staff can be resource intensive. As currently developed, each of the EBPs is a multi-component service that often requires considerable time and several staff to deliver properly. Most mental health services are under resourced, having seen their budgets cut repeatedly. As such, the EBPs may be seen as taking valuable resources away from what might be considered more basic and important services. This can be particularly true if the EBPs are not well understood and their potential outcomes not well described. However, it is important to stress again the importance of providing the EBPs with fidelity and with adequately trained staff to avoid failure and loss of confidence in these services. It may be important to restate a disheartening fact about the treatment of schizophrenia and other serious mental illnesses in North America: few people with these conditions receive well-recognized and highly

effective treatments. This reality is known as the science-to-service gap: research has shown that several interventions are effective, yet services research shows that most people who could benefit from them are unlikely to receive these services (Drake & Essock, 2009).

## Summary

Helping people with serious mental illness recover and achieve a satisfying life in the community often requires provision of services that assist with learning skills and acquiring resources that they may not presently have. People with serious mental illness and their families have a right to expect that the services they receive are the best possible — that they actually work. Public health systems have a special responsibility to purchase and provide services that work – interventions supported by rigorous research offer greater assurance of this level of quality (Morris, Day & Schoenwald, 2010).

Over the past several years, considerable research has been conducted resulting in several practices that have been shown to be effective when provided as designed and researched. These are known as evidence based services (EBPs) and the research that supports them has been summarized in a series of studies called the Schizophrenia Patient Outcomes Research Team (PORT) studies. The most recent update of the PORT study identified sixteen pharmacologic and eight psychosocial interventions that are considered evidence based. The eight PSR interventions are: assertive community treatment, supported employment, cognitive behavioral therapy, family-based services, token economy, skills training, psychosocial interventions for alcohol and substance use disorders, and psychosocial interventions for weight management. Although the PORT study focused on schizophrenia, most have assumed that the findings from major studies of individuals with schizophrenia generalize to others with serious mental illnesses, and that the interventions for people with schizophrenia can be used for people with other serious mental illnesses.

In addition to the eight EBPs, the PORT study also identified four promising practices that are emerging but do not as yet have enough empirical support to allow them to be designated as EBPs. These will be discussed in the next Interventions module.

Several important considerations must be kept in mind when the EBPs and other researched services are discussed. These include the importance of providing the researched practice with fidelity to the design and model that was found to be effective, ensuring that staff are appropriately trained and supervised, and providing services in an integrated and coordinated manner that meets the needs and wishes of the person to be served. In order to meet the challenges posed by resource intensive EBPs, it is important to ensure that adequate resources are allocated. Other factors include the need to provide all interventions, including those that are evidence based, from a recovery oriented framework and perspective that is person centered and oriented to the goals of the individual. Finally, psychologists must recognize the need to overcome resistance to change that can be exhibited by staff and administrators who genuinely believe that the services they have provided over the years have been the best available and the most effective.

## Sample Learning Activity

This exercise has two parts. For the first part, the large group is to be divided into eight small groups, which can be as small as two per small group. Each small group is to be assigned one of the EBPs. Each small group is to design an implementation plan for the EBP they have been assigned, adhering to the components of each practice and taking into account the need for fidelity, appropriately trained staff, and integration of the EBP into the existing mental health service.

The sample mental health service currently offers traditional case management, referral to traditional vocational rehabilitation services, a service they call CBT which is provided by staff with an undergraduate degree who have been given a one day seminar on CBT, social work assistance to find housing, leisure activities, and referral to a smoking cessation program. Consultation with a psychiatrist for medication evaluation is available.

For the second part of the exercise, each small group should describe how they will overcome the problems they will face in implementing the EBP. These problems could be lack of adequate resources either for the service itself or to train staff, resistance from existing practitioners, administrators who insist on offering a “lite” version of the practice, practitioners who believe there are alternatives with demonstrably equal outcomes, etc. Additionally, a consumer participant will provide feedback on the design of the EBP and the proposed solutions to overcome the systems level problems that could be encountered.

## Sample Evaluation Questions

### Question

### Correct Answer

1. Challenges to successful implementation of the EBPs include:

- a) lack of resources
- b) staff that are not adequately trained to provide the EBP
- c) consumers that have little faith in the mental health system
- d) administrators that suggest providing the EBP in ways other than it was designed
- e) all of the above
- f) a, b, d, and e above
- g) none of the above

e is correct

2. The following are reasons why psychologists might resist incorporating EBPs:

- a) EBPs constitute a change in the way many psychologists normally practice
- b) participating in an EBP team could mean that psychologists are not seen as the “doctor” or most knowledgeable team member
- c) EBPs could be seen as taking resources away from other services thought to be more important
- d) there may be insufficient resources to implement the EBP as designed
- e) all of the above
- f) a, b, and c above

e is correct

### True

### False

3) Of the EBPs, the most important is CBT because this intervention can help people learn how to “manage the demons” in their lives

F

4) Services for people with serious mental illness are now offered in the community and all of the EBPs were designed and tested for delivery in community settings to better serve the needs of the population

F

5) The importance of the PORT study is that it indicated that the eight identified EBPs are the only ones that should be offered because they can be certain to produce the identified outcomes

F

## Lecture Notes Citations

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## **Additional Resources**

American Psychological Association Recovery to Practice Initiative.  
<http://www.apa.org/pi/rtp>

## Citing the Curriculum

Citation for this Module:

American Psychological Association & Jansen, M. A. (2014). Interventions II: Evidence Based Practices. *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

Citation for the full Curriculum:

American Psychological Association & Jansen, M. A. (2014). *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

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# American Psychological Association

## Recovery to Practice Initiative Curriculum: Reframing Psychology for the Emerging Health Care Environment

### ***9. Interventions III: Promising or Emerging Practices and Supporting Services***

**NOTE:** There are three Interventions modules. They are designed to be used together and are not intended to be used separately or as stand alone modules

August 2014

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## Overview

This is the third of three modules on Interventions. The three modules are designed to be used together; they cannot stand alone as the content of any one is not sufficient to understand or provide Psychosocial Rehabilitation (PSR) interventions.

In Interventions I, the guiding principles that underlie the provision of all PSR services are discussed along with an integrative framework model that can be used to coordinate PSR services. The guiding principles are essential for the successful implementation of the interventions discussed in Interventions II and Interventions III. In Interventions II, interventions that have been proven through empirical research to achieve specific outcomes are presented; these are known as evidence based practices (EBPs). In Interventions III, interventions that have shown promise of achieving specified outcomes are presented; these are known as promising or emerging practices. Interventions III also presents supporting services that are widely acknowledged to be essential services for helping people recover from the effects of serious mental illness.

Importantly, research evidence has been accumulating that an integrated approach that combines multiple interventions within a recovery oriented context may be the most effective approach (Lyman, Kurtz, Farkas, George, Dougherty, et al., 2014; Spaulding & Deogun, 2011) and scholars are increasingly calling for such an integrated, recovery oriented system (Davidson & Chan, 2014). Such an approach must be targeted to the unique needs of each individual including those in forensic and criminal justice systems (Epperson, Wolff, Morgan, Fisher, Frueh & Huening, 2011; Strauss, 2014). In addition, it has become apparent that cognitive impairment is likely at the heart of the functional skill deficits so commonly experienced by people with serious mental illnesses (Harvey & Penn, 2010) leading to the conclusion that integrated approaches should include cognitive enhancement approaches as a fundamental component (Pfammatter, Brenner, Junghan & Tschacher, 2011; Roder, Mueller & Schmidt, 2011) and underscores the importance of social cognition for improving community functioning. Indeed, some have stated that including cognitive remediation “may result in a magnitude of change that exceeds that which can be achieved by targeted treatments alone” (Pinkham & Harvey, 2013, p. 499).

Notwithstanding the above, each of the EBPs, promising practices, and supporting services are discussed separately in the interventions modules (Interventions II and Interventions III) because as of the publication date of this curriculum, no definitive combination of approaches has been determined to be most effective, although some combination of cognitive therapies (cognitive remediation, social cognition training, cognitive behavioral therapy), supported employment, psychoeducation (client/family approaches, illness management approaches), and social and communication skills training, seems to be most promising. As the research literature evolves, additional interventions, especially those that contain a cognitive or learning component, may be identified as critically important. Furthermore, identification of which interventions work best for whom, under which

conditions, at which stage of illness, and potentially at which age of each individual, may lead to the development of personalized approaches tailored for each individual.

## Learning Objectives

At the end of this module you will be able to:

- Define promising / emerging practices and identify at least three promising or emerging practices identified in the PORT study
- Define Supporting services and identify at least three supporting services described in this module
- State at least two reasons why supporting services are important adjuncts to the EBPS and promising/emerging practices
- Identify at least three challenges faced by psychologists and other practitioners who advocate for provision of the promising practices and supporting services

## Resources

- Lecture Notes
- Required Readings
- Lecture Notes Citations
- Sample Learning Activity
- Sample Evaluation Questions
- Additional Resources

## Required Readings

Dixon, L. B., Dickerson, F., Bellack, A. S., Bennett, M., et al. (2010). The 2009 schizophrenia PORT psychosocial treatment recommendations and summary statements. *Schizophrenia Bulletin*, 36, 1, 48-70.

Miller, W. R. & Rose, G. S. (2009). Toward a theory of motivational interviewing. *American Psychologist*, 64, 6, 527-537.

Mueser, K. T., Lu, W., Rosenberg, S. D. & Wolfe, R. (2010). The trauma of psychosis: Posttraumatic stress disorder and recent onset psychosis. *Schizophrenia Research*, 116, 217-227.

Yung, A. R. (2012). Early intervention in psychosis: Evidence, evidence gaps, criticism, and confusion. *Australian & New Zealand Journal of Psychiatry*, 46, 1, 7-9.

## Activities

Complete the following activities:

- Read the lecture notes
- Read the required readings
- Engage in a learning activity related to this module
- Evaluate students' understanding of this module.

## Lecture Notes

People with lived experience of serious mental illness are strongly encouraged to be part of the delivery of the curriculum including being active participants in the delivery of the lecture. Refer to the curriculum Instruction module for additional information.

### Introduction

As described in previous modules, studies over the past several decades have shown that many people with serious mental illnesses can and do recover when they are provided with supports and services that assist them to gain the skills needed to live a satisfying and productive life. Users of mental health services have consistently said that they want the same things for themselves that every citizen wants: a family, a safe place to live, meaningful activities, adequate income, job satisfaction, and an enjoyable social life. Where children and youth are concerned, the same is true: families seeking services for children with mental health concerns want services that promote the development of competencies, and functional lifetime outcomes (Bellonci, Jordan, Massey, Lieberman, Zubritsky & Edwall, 2012).

For people with serious mental illnesses, attainment of life goals often requires substantial assistance in the form of specially designed psychosocial rehabilitation (PSR) services. While some people with serious mental illness may recover without assistance, many are unable to recover sufficiently to achieve the quality of life that they desire without these specialized services (Silverstein, 2000). Several of these specialized services have been shown in multiple randomized clinical trials to be highly effective; these are known as evidence based practices (EBPs).

In addition to the EBPs that have been proven to help people learn the skills they need to live satisfying lives, there are services that have an emerging evidence base. These are known as promising practices. There are also services that people with lived experience of mental illness cite as important and helpful. These are known as supporting services. Both of these categories of services, promising and supporting, are reviewed in this third Interventions module.

It is important to keep in mind that none of the interventions are suggested as a “cure” for serious mental illness. Rather these interventions are a means to inform individuals and their families about the illness and to help individuals achieve the life goals they have for themselves. It is also important to keep in mind that all interventions must be provided within a recovery oriented framework and perspective that is person centered, draws on the strengths and capabilities of the individual, and is oriented to the goals of the person served (Davidson, 2010; Mueser, 2012).

## Promising or Emerging Practices

In addition to the EBPs reviewed in the second Interventions module, the PORT study also indicated that reviews of treatments focused on medication management or adherence, cognitive remediation, psychosocial treatments for recent onset schizophrenia, and peer support and peer-delivered services do not yet have enough evidence to merit a recommendation as an EBP. However, each of these is an emerging area of interest and each is currently undergoing considerable research and shows promise as an emerging promising practice. These PSR practices are reviewed below.

### **Medication Management or Medication Adherence, also known as Illness Management and Recovery**

Medication is used by many individuals with serious mental illness to help decrease symptoms of the illness. Management of the dosage and side effects is a critically important aspect of a person's decision to continue to use prescribed medications. Medication is a potentially important and yet often difficult component of most treatment regimens. Taking medications, for a variety of reasons (side effects, weight gain, health concerns, etc.) can be difficult and for some individuals, non-adherence to prescribed medications may result in relapse. As a result, identifying ways to assist those prescribed medication to adhere to the treatment can be important. However, to date, there are not sufficient data to support any of the interventions designed to maintain adherence. Approaches tailored to the needs of the individual and that involve the person, his or her family, and clinicians, offer the best success to date. The consumer's concerns and preferences must be an integral part of the overall process. Use of medication should be driven by the evidence base for psychotropic medications, taking into account knowledge from the most recent research literature (Buchanan, Kreyenbuhl, Kelly, Noel, et al., 2010) and the emerging literature showing initial results related to long term use of these medications (Harrow & Jobe, 2007; Harrow & Jobe, 2013; Harrow, Jobe & Faull, 2012; McGorry, Alvarez-Jiminez & Killackey, 2013; Wunderlink, Nieboer, Wiersma, Sytema & Nienhuis, 2013).

A widely used approach consists of teaching illness management skills and usually involves a series of sessions where mental health providers help individuals with serious mental illness learn a broad range of coping strategies for living with their mental illness. Illness Management and Recovery (IMR) (Gingerich & Mueser, 2011) consists of combining a set of specific EBPs for teaching people with serious mental illness how to manage their disorder in collaboration with professional staff and family members in order to achieve their own recovery goals. The coping strategies taught in most illness management programs are a subset of those utilized in other EBPs and are designed to help individuals build healthy, wellness oriented lifestyles. Programs usually run for three to six months and consist of educational and skills building sessions. Programs are designed so that family members can also attend, with permission of the individual.

Several programs have been developed to help individuals learn the skills they need to take charge of their illness including its symptoms and its management. In addition to IMR, a peer led approach is the Wellness Recovery Action Plan (WRAP) (Copeland, 2002). WRAP and other programs that teach illness management and wellness skills have been found to help individuals feel more empowered to take charge of their illness, feel more hopeful and experience enhanced quality of life (Cook, Copeland, Jonikas, Hamilton, Razzano, et al., 2012). WRAP has also recently been found to reduce individuals' perceived need for, and use of, mental health services (Cook, Jonikas, Hamilton, Goldrick, Steigman, et al., 2013), confirming the importance of peer led illness management groups in combination with other EBPs.

Research on illness management programs indicates that provision of several key components, especially when utilizing a peer co-facilitator, can help those with serious mental illness reduce the severity of symptoms and cope better with the symptoms they have (Merinder, 2000; Mueser, Bond & Drake, 2001; Mueser, Corrigan, Hilton, Tanzman, et al., 2002). These components include:

- Psychoeducation
- Behavioral skills to learn how to take medication as prescribed and follow the medication regimen
- Cognitive behavioral strategies to assist with symptom management.

Topics covered in an illness management program include:

- Recovery strategies
- Practical facts about mental illness
- The stress-vulnerability model and coping strategies
- Building social support
- Reducing relapses
- Using medication effectively
- Coping with stress
- Coping with problems and symptoms
- Getting one's needs met in the mental health system (Mueser, Deavers, Penn & Cassisi, 2013)

Because of the breadth of the topics covered, and the short duration of most programs (3 - 6 months), in-depth training in any one of them, is not possible. As a result, most individuals will also benefit from other EBPs that provide greater coverage of given topics.

## **Cognitive Enhancement: Cognitive Remediation and Social Cognition Training**

Neuropsychological functioning is often negatively affected in people with serious mental illnesses, resulting in impaired thinking ability and inability to function well in social, educational, and work settings. The phrase “social cognition” encompasses several components of neuropsychological functioning most notably those associated with one’s ability to perceive cues related to social interaction such as perception of another’s affect and to empathize with another person, and an ability to pick up on social cues. As noted in the Overview of this module, “...it has become apparent that cognitive impairment is likely at the heart of the functional skill deficits so commonly experienced by people with serious mental illnesses (Harvey & Penn, 2010) leading to the conclusion that integrated approaches should include cognitive enhancement approaches as a fundamental component (Pfammatter, Brenner, Junghan & Tschacher, 2011; Roder, Mueller & Schmidt, 2011) and underscores the importance of social cognition for improving community functioning. Indeed, some have stated that including cognitive remediation “may result in a magnitude of change that exceeds that which can be achieved by targeted treatments alone” (Pinkham & Harvey, 2013, p. 499).”

Cognitive remediation has been shown to improve neuropsychological functioning and life skills outcomes in social, educational, and employment settings by improving cognitive functioning. Recent studies have led to the conclusion that cognitive remediation holds the greatest promise when delivered in conjunction with other rehabilitation interventions such as supported employment. Importantly, in order to impact on aspects of social cognition (also important in a variety of settings such as work, education, social interactions, etc.), cognitive remediation has been found especially effective when combined with social cognition training which includes emotional processing skills and affect recognition, illness management skills, attributional bias and mentalizing exercises (Horan, Kern, Tripp, Helleman, et al., 2011; Kurtz & Richardson, 2012; Lindenmayer, McGurk, Khan, Kaushik, Thanju, et al., 2013; Roder, Mueller & Schmidt, 2011).

Cognitive remediation programs generally provide computer assisted training exercises designed to help clients re-learn cognitive skills aimed at improving learning, memory, attention, concentration, and executive functions that control and regulate adaptive abilities and behaviors, such as initiating, monitoring and changing behavior as needed. Several studies have found increased cognitive functioning after remediation efforts (Anaya, Martinez, Ayuso-Mateos, Wykes, Vieta & Scott, 2012; Fisher, Holland, Subramaniam & Vinogradov, 2009; McGurk, Twamley, Sitzler, McHugo, et al., 2007; Pfammatter, Junghan & Brenner, 2006; Wykes, Reeder, Landau, Everitt, et al., 2007) and some studies have found enhanced employment outcomes when cognitive remediation is paired with supported employment (Lindenmayer, McGurk, Mueser, Kahn, et al., 2008; McGurk, Mueser & Pascaris, 2005), although one recently published study found these effects mainly for those with lower community functioning capability (Bell, Choi, Dyer & Wexler, 2014). Recently evidence has begun to accumulate which indicates that emotional distress and negative

symptoms may also be positively impacted (Sanchez, Pena, Bengoetxea, Ojeda, Elizagarate, et al., 2014). Other studies have found only small effects of cognitive remediation efforts on neuropsychological or functional outcomes (Dickinson, Tenhula, Morris, Brown, et al., 2010).

Because of the importance of the range of neuropsychological processes for attainment of one's life goals, this is an important area where more research is needed to identify the conditions under which maximum benefit can be obtained from these interventions.

### **Psychosocial Treatments for Recent Onset Schizophrenia**

Although serious mental illnesses can strike adults in the prime of their lives, these illnesses most frequently strike young people between the ages of 15 and 26 (Dickinson, Tenhula, Morris, Brown, et al., 2010), with a median age at which symptoms first appear of 14 (National Health Policy Forum, 2009).

Often, people with serious mental health and substance use disorders become ill early in their lives when the skills needed for success in life are just developing. When this happens, thinking ability is often severely compromised because of the negative effects these disorders have on cognitive processing capabilities. Education and work are disrupted, and often stopped completely along with the ability to form meaningful relationships with family and friends. Frequently, there is a period of symptomatology that occurs before full blown psychosis develops. This period has been called the "prodromal period", and those in this state have been said to be at "ultra high-risk", or to be experiencing an "attenuated psychosis syndrome" (Yung, Woods, Ruhrman, Addington, Schultze-Lutter, et al., 2012); the rate of onset of a psychotic disorder has been shown to be thirty six percent within three years (Fusar-Poli, Bonoldi, Yung, Borgwardt, Kempton, et al., 2012). Recently, clinical staging models have been applied to those with mental health disorders in an effort to help clinicians identify the best course of action for those who may not have progressed to full blown psychosis and to help prevent progression (Cross, Hermens, Scott, Ottavio, McGorry & Hickie, 2014; Hickie, Scott, Hermens, Naismith, Guastella et al., 2013). Previous models have focused on symptoms usually seen in early stages of illness such as anxiety and depression but do not account for the symptoms that may indicate signs of more serious illness. Innovatively, the model described by the authors above incorporates a range of symptoms and syndromes within a single staging model, thus allowing for attention to potential developing psychosis.

Although there are many factors that influence functional outcomes, there is growing evidence that early intervention with pharmacologic and psychosocial interventions during the first episode of psychosis may lead to improved outcomes (Baksheev, Allott, Jackson, McGorry & Killackey, 2012; Bertelsen, Jeppesen, Petersen, Thorup, et al., 2008; Bird, Premkumar, Kendall, Whittington, et al., 2010; Ehmann, Yager & Hanson, 2008; Marshall & Rathbone, 2011; Tandon, Keshavan & Nasrallah, 2008) and may prevent or delay relapse (Álvarez-Jiménez, Parker, Hetrick, McGorry, et al., 2011). Early intervention programs



generally include the provision of multimodal psychosocial interventions (CBT, family based psychoeducation, illness management, educational and vocational interventions), pharmacotherapy, and some form of case management with lower case-loads and an assertive approach to treatment, all within the context of intervening as early as possible. Interestingly, recent research has shown that omega-3 fatty acids (fish oil) prevented development of psychosis for the duration of the study period (12 months) (Amminger, Schafer, Papageorgiou, Klier, et al., 2010) and this could be a promising intervention to help the person avoid use of psychotropic medications. Confirmatory studies of this potentially helpful adjunct are needed.

Despite the promising results of early intervention research, the evidence also suggests that the effects are not sustained beyond the intervention period and continued intervention may be needed (Bertelsen, Jeppesen, Petersen, Thorup, et al., 2008; Bird, Premkumar, Kendall, Whittington, et al., 2010; Bosanac, Patton & Castle, 2010; Gleeson, Cotton, Alvarez-Jimenez, Wade, Gee, et al., 2013; McGorry, Nelson, Goldstone & Yung, 2010; Norman, Manchanda, Malla, et al., 2011; Pretia & Cella, 2010), especially during what is considered the five year critical period from onset of psychotic symptoms (Addington, Leriger & Addington, 2003; Birchwood, 2000; Birchwood, Todd & Jackson, 1998; Harrison, Hopper, Craig, Laska, et al., 2001; McGlashan, 2006; McGorry, 2002; Perkins, Gu, Boteva, et al., 2005; Wyatt & Hunter, 2001).

At the same time, emerging research is indicating that use of pharmacologic interventions following remission from first episode psychosis (FEP) may need to be used at much lesser doses and potentially discontinued altogether. In one of the first studies in this area, Harrow & Jobe identified individuals with schizophrenia who achieved greater symptom and functional recovery at all follow up periods over a fifteen year period (Harrow & Jobe, 2007). These results were confirmed following additional follow up at twenty years post initial hospitalization. The authors also measured individuals pre-morbid characteristics and identified greater levels of resiliency, better pre-morbid developmental achievements, less vulnerability to anxiety, better neurocognitive skills, and less vulnerability to psychosis as factors that contributed to individuals' better outcomes (Harrow, Jobe & Faull, 2012; Harrow & Jobe, 2013).

In another study, Wunderlink and colleagues showed that following remission from FEP, discontinuing psychotropic medications over an 18 month period resulted in initially greater rates of relapse at three years post relapse, but at seven years, the rate of functional recovery was twice that for the discontinuation group compared to the maintenance therapy group with relapse rates at the seven year follow up similar in both groups (Wunderlink, Nieboer, Wiersma, Sytma & Nienhuis, 2013). Clearly, initially increased relapse rates are not desirable but may be an acceptable price to pay for significantly greater functional capability over the long term (McGorry, Alvarez-Jimenez & Killackey, 2013).

The results of these and other studies related to long term use of neuroleptic medications are an exciting development that needs to be watched closely by psychologists and other

mental health practitioners who may be prescribing psychotropic medications and by all those working with individuals with serious mental illnesses.

Somewhat distinct from the issue of long term medication use is a related but slightly different aspect of medication use, i.e., duration of untreated psychosis (DUP). Evidence suggests that the longer an individual remains without treatment after evidencing psychosis, the poorer the ultimate outcome (Marshall, Lewis, Lockwood, Drake, Jones & Croudace, 2005). There is also evidence that reducing DUP leads to better long term outcomes (McGlashan, Evensen, Haahr, Hegelstad, et al., 2011). This is also an important and emerging area of intense research interest that needs to be followed carefully.

While there are conflicting views about the importance of providing early intervention services (Yung, 2012), this is an area that many see as one of the most important, and considerable research is underway in this area. This is because the real tragedy of serious mental illness is the loss of life's potential that happens when proven rehabilitative treatments are not provided. Engaging individuals who are experiencing a first episode of psychosis, especially those who are youth is especially important and may be facilitated by developmentally appropriate interventions (Green, Wisdon, Wolfe & Firemark, 2012). Likewise, providing intensive case management using an assertive community treatment model has been shown to facilitate greater social networks and may lead to improved clinical outcomes as a result of establishing or maintaining relationships with family and friends (Tempier, Balbuena, Garety & Craig, 2012).

### **Peer Support and Peer Delivered Services**

Participation of consumers in the design and delivery of mental health services is one of the hallmarks of a mental health system that truly supports the principles of recovery. There are many models of consumer involvement in the delivery of services and peer support is the most widely known of these.

People with lived experience of mental illness consistently report that having the support of others who have gone through what they are going through is one of the most important and helpful services; several studies have confirmed these perceptions (Dumont & Jones, 2002; Nelson, Ochocka, Janzen & Trainor, 2006; Piat, Sabetti, Couture, Sylvestre, et al., 2009).

Peer support programs are provided by individuals who have experienced a serious mental illness themselves and who have recovered sufficiently to be helpful to others who have similar problems. Peers listen, share their own experiences, and offer support, hope, encouragement, education, and practical suggestions. Peer leaders are trained to engage in active and supportive listening, and are trained to lead groups themselves or to work individually with current consumers. Training in basic communication skills may be needed to ensure that the peer support worker is skilled enough to offer a helpful intervention. Many believe that peer support programs help to normalize the experience of serious mental illness while traditional treatment tends to medicalize and stigmatize it.

In addition to peer support services, other types of peer delivered services are currently being delivered and researched. These can include peers serving as regular members of the mental health clinical team and peers organizing and running independent services. To date, there has not been sufficient research on these services to support their effectiveness, but given the importance that persons with lived experience attach to them, much more work in this area is needed.

Peer support is currently the focus of considerable research interest to determine if there is enough empirical evidence to include it as an EBP. Whether or not peer services are ultimately supported by research evidence, there is no question that those receiving services value it greatly. Because of the importance of peer support services, a full module of this curriculum entitled Peer Delivered Services, is devoted to the practice. Additional information is also available from the InterNational Association of Peer Supporters at [www.inaops.org](http://www.inaops.org).

## **Supporting Services**

In addition to the EBPs and the promising or emerging practices, there are several services that support individuals with serious mental illness and help them achieve a healthy and satisfying life. Many of these are supported by initial research, others are critically important to avoid life threatening situations, and others are needed to help people achieve a normal and successful life in the community. These are often called supporting services and are part of a comprehensive PSR system of services. Each of these supporting services is discussed below.

### **Motivational Interviewing**

Motivational interviewing has been shown, in several clinical trials, to be a highly effective intervention that assists people to make changes in their lives (Miller & Rose, 2009). The strategy is particularly important when individuals are confronting behaviors that are difficult to change, such as addictive behaviors, but has been shown to be useful for a wide variety of situations and populations, including those with chronic mental health disorders (Arkowitz, Westra, Miller & Rollnick, 2008; Hettema, Steele & Miller, 2005; Lundahl, Kunz, Brownell, Tollefson, et al., 2010; Rollnick, Butler, Kinnersley, Gregory, et al., 2010; Rubak, Sandbaek, Lauritzen & Christensen, 2005). Motivational interviewing is considered an EBP for substance abuse. Research indicating the efficacy of the approach for people with serious mental illnesses is not conclusive (Barrowclough, Haddock, Wykes, Beardmore, et al., 2010) and it has not yet been designated an EBP or a promising practice for these conditions.

A major tenet of motivational interviewing is acceptance of the fact that clients who need to make changes in their lives approach counseling at different levels of commitment to change their behavior. The goal of motivational interviewing is to help individuals explore their ambivalence about their behavior. Motivational interviewing is non-judgmental and

non-confrontational and success is highly dependent on therapist training and empathic ability (Amrhein, Miller, Yahne, Knupsky, et al., 2004; Health Canada, 2008; Houck & Moyers, 2008; Miller & Mount, 2001; Miller & Rose, 2009; Miller, Yahne, Moyers, Martinez & Pirritano, 2004).

## **Supported Housing**

Having a place to live is one of the most fundamental and important aspects of life. Yet, people with serious mental illnesses are often either homeless or at risk of becoming homeless (Padgett, 2007). Many believe that having decent, stable, affordable housing of one's choice is the first step toward achieving recovery. For this reason the slogan "Housing First" has developed as one of the cornerstones of recovery services.

Research is currently underway to determine the benefits of providing housing before other services, especially for people with co-occurring disorders. Many studies have found decreased use of alcohol and drugs, reduced costs for police services, emergency room treatment, increased housing stability, and decreased psychiatric hospitalization when people have a stable place to live (Culhane, Metraux & Hadley, 2002; Gulcur, Stefancic, Shinn, Tsemberis, et al., 2003; Lipton, Siegel, Hannigan, Samuels, et al., 2000; Pearson, Montgomery & Locke, 2009).

Most people prefer to live independently and many people with serious mental illnesses do live independently. Others need varying levels of support. There are a range of options for helping people with serious mental illness live in the community. Supported housing is an intervention designed to assist people with serious mental illnesses find and maintain stable residences with the ongoing support of mental health professionals (Chilvers, Macdonald & Hayes, 2010). Models range from providing support for people living independently with casual support through to housing where staff persons are on site twenty four hours per day.

Often individuals need information and skills training to help them learn how to manage their home and frequently need treatment for co-occurring substance use disorders. Although information and skills development related to obtaining and maintaining appropriate housing are sometimes integrated into other clinical interventions, these can be provided as a separate service. Recent reviews have found that the best outcomes were achieved when housing was provided together with support utilizing the comprehensive assertive community treatment model (Coldwell & Bender, 2007; Nelson, Aubry & Lafrance, 2010; Rogers, Kash & Olschewski, 2009).

Considerable research on housing outcomes for individuals with mental health and addictive disorders has been conducted over the past several years. Outcome studies have generally concluded that functioning can improve, social integration can be facilitated, and residents are generally more satisfied in supported housing compared with conventional hospital care (Best, Boothroyd, Giard, Stiles, et al., 2006; Clarke, Febbrara, Hatzipantelis & Nelson, 2005; Fakhoury, Murray, Shepherd & Priebe, 2002; Forchuk, Ward-Griffin, Csiernik

& Turner, 2006; Parkinson, Nelson & Horgan, 1999; Rog, 2004). Some programs provide treatment for co-occurring substance use disorders with support embedded with the housing program and these have shown reduced service system costs (Gilmer, Stefancic, Ettner, Manning, et al., 2010; Mares & Rosenheck, 2009).

A recent comprehensive synthesis of the research literature found the following:

Overall, our synthesis suggests that supported housing can improve the living situation of individuals who are psychiatrically disabled, homeless and with substance abuse problems. Results show that supported housing can help people stay in apartments or homes up to about 80% of the time over an extended period.... Housing services appear to be cost effective and to reduce the costs of other social and clinical services. In order to be most effective, intensive case management services (rather than traditional case management) are needed and will generally lead to better housing outcomes. Having access to affordable housing and having a service system that is well-integrated is also important.... Supported housing can improve clients' quality of life and satisfaction with their living situation.... In addition, rapid entry into housing, with the provision of choices is critical (Rogers, Kash & Olschewski, 2009, p. 1).

To date, the most solid evidence for the benefits of assisting people achieve stable housing indicates that permanent, supportive housing appears to achieve the best results. Models of permanent, supportive housing are rated more positively by individuals and led to reduced homelessness, increased housing tenure, and decreased emergency room visits and hospitalization (Rog, Marshall, Dougherty, George, Daniels, et al., 2014). Additional research is needed to identify the best housing solutions for people with serious mental illnesses, many of whom have co-occurring substance use disorders. As mentioned, current results indicate that provision of safe and affordable supportive housing can help homeless individuals with serious mental illness remain in stable housing, use adjunct social services less and achieve stability. Providing stable housing and decreasing homelessness are desirable goals irrespective of other benefits.

### **Supported Education**

Assisting individuals with serious mental illnesses to resume their normal educational trajectory is increasingly recognized as vital to their recovery and ability to return to a normal life. This is particularly important now as recent advances in pharmacologic treatments have allowed young persons who are newly diagnosed with mental illness to avoid long term hospitalization and more quickly resume the developmental trajectory of their lives.

The primary aim of supported education is to provide opportunities, resources, and supports to people with serious mental illnesses so that they may gain admittance to, and succeed in the pursuit of post-secondary education (Isenwater, Lanham & Thornhill, 2002; Mowbray, Collins & Bybee, 1999; Unger, Pardee & Shafer, 2000). The practice is

increasingly recognized as one that is needed in a comprehensive service delivery system for people with serious mental illnesses.

Although supported education was developed primarily to help people return to postsecondary education, the principles and practices also apply to adolescents and adults who are completing high school or participating in adult education. Services assist people with a diagnosis of mental illness return to education and become better prepared to achieve their learning and recovery goals and/or become gainfully employed in the career of their choice (Mowbray, Brown, Furlong-Norman & Soydan, 2002). Supported education services usually consist of a helper who provides assistance to an individual who is applying for, or attending an educational institution and who needs help due to functional limitations associated with cognitive processing deficits. A range of services tailored to the needs of the individual, is generally recommended (Leonare & Bruer, 2007).

Supported education has been shown to assist individuals to successfully complete their educational goal (Robson, Waghorn, Sherring & Morris, 2010). People with serious mental illnesses indicate it has been helpful (Collins, Mowbray & Bybee, 2000; Gutman, Schindler, Furphy, Klein, et al., 2007); additional research is needed on this potentially valuable intervention.

The following are considered critical components in a supported education program:

- A supported education team/specialist designated to work with consumer-students
- Supported education programs have no non-educational eligibility requirements for entrance into the program
- Supported education specialists complete educational assessments with consumer-students
- Communication and collaboration occur between all stakeholders
- Supported education programs offer confidence and knowledge building activities
- Supported education programs offer preparatory options
- Preparatory classes are not required by supported education programs for school enrolment
- Programs offer support and assistance to acquire necessary resources for school attendance
- Programs provide enrollment and educational supports (Ratzlaff, McDiarmid, Marty & Rapp, 2005).

### **Interventions to Provide Trauma Informed Care**

A large proportion of those with serious mental illness have experienced trauma. Trauma can be from many sources including physical, sexual, and emotional abuse, combat or war experiences, major illness, witnessing abuse or other traumatic events happening to others,

catastrophic events, etc. Many individuals are traumatized by the mental health system itself due to the stigma, lack of respect, uncaring attitudes and sometimes dehumanizing and even abusive practices that are demonstrated even today by some mental health professionals.

The severity of the trauma experienced by the majority of those in the system was summarized by Jennings, 2008:

The kinds of trauma experienced by persons who are or who become recipients of public mental health services are usually not associated with “single blow” traumatic events (Terr, 1991) such as natural disasters, accidents, terrorist acts, or crimes occurring in adulthood such as rape and domestic violence (Giller, 1999). Rather, the traumatic experiences of adults, adolescents and children with the most serious mental health problems are interpersonal in nature, intentional, prolonged and repeated, occur in childhood and adolescence, and may extend over years of a person’s life. They include sexual abuse or incest, physical abuse, severe neglect, and serious emotional and psychological abuse...They are traumatized further by coercive interventions and unsafe psychiatric environments (Jennings, 1994; Cusack, et al., 2003; Frueh, et al., 2000; Frueh, et al., 2005; Grubaugh, 2007; Robins, 2005) and at times sexual and physical abuse in inpatient or institutional settings, jails, and prisons (p. 2).

And from Herman:

The betrayal and relational damage occurring when a child is repetitively abused and neglected sets up lifetime patterns of fear and mistrust which have enormous impacts on his or her ability to relate to others and to lead the kind of life he or she wants. Recovery cannot occur in isolation. It can take place only within the context of relationships characterized by belief in persuasion rather than coercion, ideas rather than force, and mutuality rather than authoritarian control—precisely the beliefs that were shattered by the original traumatic experiences (Herman, 1992, p. 22).

Experiencing a psychotic episode for the first time can be highly traumatic and can lead to full PTSD or to PTSD symptoms. The trauma can emanate from terror experienced as a result of the psychotic symptoms themselves or from experiences encountered in the treatment system, or both (Mueser, Lu, Rosenberg & Wolfe, 2010).

Not everyone who witnesses or experiences trauma develops PTSD or less severe trauma reactions, but many do. Estimates of those who have experienced or witnessed trauma and subsequently developed a traumatic reaction range from 27 to 74 percent with reactions ranging from somatic concerns, non-specific distress, anxiety, depression, and simple or complex PTSD (Norris, 2005). Individuals experiencing their first psychotic episode who experienced physical or sexual abuse more often attempted suicide and had poorer treatment outcomes than those without similar histories of abuse (Conus, Cotton, Schimmelman, McGorry, et al., 2010). Epidemiologic research indicates that several factors play a part in determining whether or not an individual will develop a trauma related

disorder. These include age at which the trauma was experienced with children being most vulnerable, emotional resilience, socio-economic status (developing versus developed country status), and severity of the traumatic event (Norris, Byrne, Diaz & Kaniasty, 2002).

Women who have experienced violence, physical, emotional, and sexual abuse and trauma often have co-occurring mental health and substance abuse problems and are at special risk (Ad Hoc Working Group on Women, Mental Health, Mental Illness and Addictions, 2006; Elklit & Shevlin, 2011). Homeless women are more vulnerable than homeless men, are poorer, and often have additional stressors due to child care responsibilities (Harris & Bachrach, 1990). Due to their increased vulnerability and poverty, women are also more likely to be unable to control sexual situations and may be more often exposed to HIV/AIDS and other sexually transmitted diseases (Darves-Bornoz, Lemperiere, Degiovanni & Gaillard, 1995). The result is that women have very different treatment needs than men (Bently, 2005). Women that have been abused by men will likely be unable to work through those issues in a mixed group – a mixed trauma group can actually exacerbate their trauma. Services offered in women only groups are essential for women who have been abused both to help them recover and to avoid exacerbating their trauma. A PTSD group for women in these circumstances is essential. Some trauma services (Najavits, 2006) have been designed or modified specifically for women but their availability is typically limited.

Children and adolescents can also be significantly affected by traumatic experiences including severe adversity (sexual abuse, physical abuse, emotional/psychological abuse, neglect, parental death, and bullying) and develop PTSD, which is highly prevalent in those who have experienced trauma. There is accumulating evidence that children who experience severe adversity, physical abuse and especially those who are repeatedly abused are at increased likelihood for developing psychosis (Frounfelker, Vorhies Klodnick, Mueser & Todd, 2013; Rosenberg, Lu, Mueser, Jankowski & Cournos, 2007; Shevlin, Dorahy & Adamson, 2007; Varese, Smeets, Drukker, Lieveerse, Lataster, et al., 2012) and that sexual trauma may even be a contributing factor in the development of psychosis for some individuals (Thompson, Nelson, Yuen, Lin, Amminger, et al., 2014). Additionally, the more trauma a child experiences the greater the likelihood of increased severity of psychotic symptomology (Lu, Yanos, Silverstein, Mueser, Rosenberg, et al., 2013).

Interventions must be specifically geared toward helping people with serious mental illnesses work through the devastating effects of the traumatic experiences they have had. According to SAMHSA:

Trauma-specific treatment services are “interventions designed to address the specific behavioral, intrapsychic, and interpersonal consequences of exposure to sexual, physical, and prolonged emotional abuse” (Substance Abuse and Mental Health Services Administration, 2000).

Harris and Fallot, 2001 described a trauma informed system as:



A “trauma-informed” system is one in which all components of a given service system have been reconsidered and evaluated in the light of a basic understanding of the role that violence plays in the lives of adults, children and adolescents and families or caregivers seeking mental health and addictions services (Harris & FalLOT, 2001). A “trauma informed” system uses that understanding to design service systems that accommodate the vulnerabilities of trauma survivors and allows services to be delivered in a way that will avoid inadvertent re-traumatization and will facilitate consumer participation in treatment. It also requires, to the extent possible, closely knit collaborative relationships with other public sector service systems serving these clients and the local network of private practitioners with particular clinical expertise in “traumatology”.

In contrast, trauma specific services are described as:

“Trauma-specific” services are designed to treat the actual sequelae of sexual or physical abuse trauma. Examples of trauma-specific services include grounding techniques which help trauma survivors manage dissociative symptoms, desensitization therapies which help to render painful images more tolerable, and behavioral therapies which teach skills for the modulation of powerful emotions (Harris & FalLOT, 2001). Treatment programs designed specifically for survivors of childhood trauma are consistent on several points: the need for respect, information, connection, and hope for clients; the importance of recognizing the adaptive function of “symptoms;” and the need to work in a collaborative empowering way with survivors of abuse (Saakvitne, 2000).

A recent review of interventions for people with serious mental illness and severe trauma found that both cognitive behavioral treatment (combined with psycho-education about PTSD, breathing retraining, and cognitive restructuring) (Mueser, Rosenberg, Xie, Jankowski, Bolton, Lu, et al., 2008) and exposure therapy (combined with group therapy focused on education, relaxation training and social skills building) (Frueh, Grubaugh, Cusack, Kimble, Elhai & Knapp, 2009) were found to be effective, with the cognitive behavioral treatment program evaluated in the largest clinical trial conducted to date. This comprehensive review notes that continued research is needed to address the extremely important but often overlooked issue of trauma experienced by people with serious mental illnesses (Grubaugh, Zinzow, Paul, Egede & Frueh, 2011).

With respect to psychological treatments for children and adolescents with PTSD, a recent review found that all psychological treatments studied were effective at helping those in this age group recover. CBT was found to be particularly effective (Gillies, Taylor, Gray, O'Brien, & D'Abrew, 2012).

Elements common to many treatment modalities for PTSD include education, exposure, exploration of feelings and beliefs, and coping-skills training. CBT is common to many of

the treatment paradigms. Components of these paradigms are listed in the excerpt below, taken from the website of the U.S. National Center for PTSD:

Cognitive-behavioral therapy (CBT) involves working with cognitions to change emotions, thoughts, and behaviors. Exposure therapy is one form of CBT that is unique to trauma treatment. It uses careful, repeated, detailed imagining of the trauma (exposure) in a safe, controlled context to help the survivor face and gain control of the fear and distress that was overwhelming during the trauma. In some cases, trauma memories or reminders can be confronted all at once ("flooding"). For other individuals or traumas, it is preferable to work up to the most severe trauma gradually by using relaxation techniques and by starting with less upsetting life stresses or by taking the trauma one piece at a time ("desensitization") (www.ncptsd.va.gov).

Along with exposure, CBT for trauma includes:

- Learning skills for coping with anxiety (such as breathing retraining or biofeedback) and negative thoughts (cognitive restructuring)
- Managing anger
- Preparing for stress reactions (stress inoculation)
- Handling future trauma symptoms
- Addressing urges to use alcohol or drugs when trauma symptoms occur (relapse prevention), and
- Communicating and relating effectively with people (social skills or marital therapy).

Alcohol and drug abuse commonly occur with PTSD because of the numbing effect of the drugs and their ability to help the person escape from the high levels of anxiety experienced. It is important to treat the substance use disorder along with the trauma disorder. Given the high co-morbidity of substance use disorders among those with mental health disorders and the prevalence of exposure to violence, abuse, and other traumatic experiences, concurrent treatment for these conditions can be critical. A manualized program not developed for people with serious mental illnesses but developed specifically for co-occurring substance abuse disorders and PTSD is called Seeking Safety. Seeking Safety is a CBT based program that has been found to be effective for a range of individuals with PTSD (Najavits, 2006; Najavits & Hien, 2013); a version of this program adapted for women who have experienced severe trauma is also available.

Pharmacotherapy is often also an important component of treatment and can reduce the anxiety, depression, and insomnia often experienced with trauma reactions and PTSD, making it possible for individuals to participate in treatment. Additional information can

be obtained from a SAMHSA webinar, available at <http://www.dsgonline.com/rtp/webinars/1.25.2012.html>.

## **Smoking Cessation**

The reasons why so many people with serious mental illnesses smoke and find it so difficult to quit are only now beginning to emerge. The importance and urgency of helping people stop smoking has recently been well stated by Schroeder and Morris:

Tobacco use exerts a huge toll on persons with mental illnesses and substance abuse disorders, accounting for 200,000 of the annual 443,000 annual tobacco-related deaths in the United States. Persons with chronic mental illness die 25 years earlier than the general population does, and smoking is the major contributor to that premature mortality. This population consumes 44% of all cigarettes, reflecting very high prevalence rates plus heavy smoking by users. The pattern reflects a combination of biological, psychosocial, cultural, and tobacco industry-related factors. Although provider and patient perspectives are changing, smoking has been a historically accepted part of behavioral health settings. Additional harm results from the economic burden imposed by purchasing cigarettes and enduring the stigma attached to smoking. Tailored treatment for this population involves standard cessation treatments including counseling, medications, and telephone quitlines. Further progress depends on clinician and patient education, expanded access to treatment, and the resolution of existing knowledge gaps (Schroeder & Morris, 2010).

Smoking rates may be as high as 80 – 90 percent among people with serious mental illnesses compared to prevalence rates of 20 – 30 percent in the general population (Department of Family and Community Medicine, 2000). Many of those with serious mental illnesses are very poor, and cigarettes consume a large proportion of their discretionary spending. An additional factor is that it is harder to achieve community integration when also experiencing stigma related to tobacco use (Schroeder & Morris, 2010).

Research indicates that several factors are common to successful smoking cessation programs. These include:

- Advice to quit given by a physician
- Nicotine pharmacotherapy (both over the counter and by prescription)
- Counselling that is both long term and intensive, and
- A supportive public health environment and approach (World Health Organization, 2003).

Other interventions have also been found to be useful including hypnosis, and telephone quitlines, and these can be considered to be adjunct interventions to those that have the most research evidence behind them. Recent research has found that in addition to the factors above, social support from friends and family and smoking cessation programming that is relevant and easily accessible to people with serious mental illnesses can help them quit smoking (Dickerson, Bennett, Dixon, Burke, Vaughan, et al., 2011).

Due to the very real and serious health consequences of smoking, interventions to help people with serious mental illnesses stop smoking should be a high priority in all systems of mental health care. Additional information about the health issues and difficulties people with serious mental illnesses have when trying to quit smoking can be found in the Health Disparities module of this curriculum.

### **Health Education**

Because symptoms of mental illness often begin in adolescence, many young people have not learned skills needed for successful independent living. These include skills for staying healthy and safe, especially when it comes to avoiding risky sexual encounters and behaviors.

Emerging evidence suggests that young people with serious mental illness are at greater risk of contracting sexually transmitted diseases than their non-ill peers and that these young people have greater needs for preventive interventions (Brown, Lubman & Paxton, 2011).

Over the past two decades, the international community has reiterated calls for integrating and strengthening linkages between sexual and reproductive health services, and strategies and services for prevention and treatment of HIV/AIDS. Individuals with serious mental illness are often the most vulnerable to sexual exploitation and abuse, and the least likely to have information needed to protect themselves. Women with serious mental illness are recognized as the most vulnerable of all, but both men and women need the tools to lead safe, healthy, and productive lives in the community.

While some of this information would be expected to be covered in skills training programs (e.g., communication skills related to making friends, learning how to initiate or refuse intimate encounters, etc.), information about safe sex, HIV/AIDS and other STDs, information about the risks of drug injection and about safe injection practices, and other more general health information, is appropriately provided by a broadly trained health professional and should be provided to individuals who are at risk of engaging in unhealthy behaviors. An indication of the universal acceptance of the importance of providing comprehensive health information comes from the United Nations, whose Task Force on Child Health and Maternal Health of the UN Millennium Project stated:

Universal access to sexual and reproductive health information and services would have far-reaching effects for both ... maternal health and child health goals and for

virtually every other goal, including those for HIV/AIDS, gender, education, environment, hunger and income poverty (United Nations, 2005).

### **Clubhouses, Drop-in Centers, and Recovery Education Centers**

Other service models such as clubhouses, drop in centers, and recovery education centers have been developed, but until recently, there has been little research to support them. The clubhouse model was the first rehabilitation intervention developed and it began at Fountain House in New York in 1948. Integral to the model are daily activities that provide individuals the opportunity to participate in all of the work activities of the clubhouse itself, from administration to outreach, to hiring, training and evaluation of staff, and including research on the effectiveness of the clubhouse. Fountain House also originated the concept of transitional employment and broadened the concept to supported employment, the practice that was ultimately formalized into the EBP in use today. In the late 1950s, the model was broadened to include housing supports and case management services were added. In the late 1990s, evaluation and links to medical and substance abuse treatment services were added, thus offering the full range of interventions. Currently, a wide array of supportive services is provided, all aimed at helping individuals live as independently and productively as possible. The Fountain House model has been replicated in countries all over the world and an intensive training program is offered at several sites to organizations that are interested in starting a clubhouse. The core elements of the Fountain House model are those that research has consistently found to be necessary components of successful mental health treatment systems:

- Education for clients and families
- Skills training for work and community living
- Case management
- Medication management, and
- Clinical follow up.

Recently, research has begun to accumulate on the effects of Fountain House and the clubhouse model. These studies have found that where the clubhouse adheres to the Fountain House model, members are more successful in paid employment, have longer job tenure, and move on to employment that is less supported than do those who are similarly ill and in other parts of the mental health treatment system, but not part of a structured clubhouse (Macias, Rodican, Hargreaves, Jones, et al., 2006; McKay, Johnsen, Banks & Stein, 2006; Schonebaum, Boyd & Dudek, 2006).

The Fountain House model has been subjected to rigorous research focused on variables not directly linked to its activities. Initial results from studies of cost effectiveness have shown lowered costs due to reduced recidivism (Cowell, Pollio, North, et al., 2003; McKay, Yates & Johnsen, 2007), and studies of physical well-being have indicated wellness benefits

as well (Pelletier, Ngyuen, Bradley, et al., 2005; Pernice-Duca, 2008; Schiff, Coleman & Miner, 2008).

It is important to note that, as with the other PSR practices, fidelity to the model that has been researched and shown to be effective, is critical to achieving outcomes for persons in recovery. For drop-in centers and clubhouses that do not adhere to the Fountain House model, this has not typically been the case as many of these have sprung up as well intentioned programs but with little regard for fidelity to the original model. As discussed in the previous module, fidelity to the researched model is important.

## **Leisure Services**

People with serious mental illnesses often have difficulties accessing and enjoying social relationships and leisure activities. The reasons for this range from lack of skills to build and sustain friendships, to lack of knowledge about community resources, to social isolation and stigma associated with mental illnesses. Whatever the reasons, individuals are frequently isolated and do not participate in leisure and social pursuits, especially when these involve other people or group activities. Because of their broad ranging effects, many, if not most, of the interventions described above are effective in assisting individuals to achieve greater participation in leisure activities and to be successful in activities in the personal life domain. But, often specialized leisure programs are needed to help people become comfortable integrating into regular community social activities and learn how to access regular social and leisure programming in the community where they live.

In addition to acquiring social and leisure skills, leisure activities can play a key role in the restoration and maintenance of mental health. Leisure can be an essential means of developing self esteem, building confidence and making connections with other people. Some literature exists regarding the effects of interventions aimed specifically at assisting individuals to benefit from leisure activities and a sampling of this literature is presented below.

For more than a decade leisure scholars have suggested that leisure could help people cope with stress (Iwasaki & Mannell, 2000) and some have found that stressors negatively impact immediate adaptational outcomes such as coping effectiveness, coping satisfaction, stress reduction and longer-term outcomes including health and stress (Hutchinson, Loy, Kleiber & Dattilo, 2003). High levels of stress and depression have been found in homeless women (Banyard & Graham-Bermann, 1998) and leisure activities can be one component in assisting them to cope with these effects (Klitzing, 2003).

Moderate intensity exercise or even rest, which may be considered forms of leisure, have been shown to have reductions on measures of psychological distress including depression, confusion, fatigue, tension, and anger (Bartholomew, Morrison & Ciccolo, 2005). These effects have been found to extend to those with a diagnosis of schizophrenia (Torres-Carbajo, Olivares, Merino, Vazquez, et al., 2005). Additionally, when therapeutic recreation was included as part of a social learning program, therapeutic recreation was found to

increase appropriate behaviors over time for residents with severe and persistent schizophrenia (Pestle, Card & Menditto, 1998). Leisure programs designed to increase knowledge and skills, and build confidence are an important part of the PSR armamentarium of services.

### **Personal Life/Daily Living Skills**

Because symptoms of serious mental illness often appear during a young person's transition to adulthood, skills needed for successful community integration are frequently not learned. Services that focus on helping people manage aspects essential to daily living are important and include personal care or self management, nutrition, physical health and safety, budgeting and finance, housekeeping, transportation, coping with stress, relationships, and the use of community resources.

Many of the skills useful for the above activities can be learned as part of the practices described in earlier sections of this module or in the previous Interventions modules. For example, skills training, an EBP covered in Interventions II, can be very broad and encompass training in any skill area needed by the individual. Programs in medication management and weight management (also covered in the second Interventions module) encompass several of the identified skills. Others such as building and maintaining relationships, are most often facilitated by peers and programs in family psychoeducation and skills training (see Interventions II). However, if the skill sets needed for successful management of one's life are not included in other programs, service systems must develop programs to ensure that people who need essential skills for successful participation in community life receive such training and become proficient at using these skills.

### **Challenges**

There are two principal challenges related to provision of the interventions presented in this module. The first is that while both the promising practices and the supporting services make intuitive sense, there is yet not sufficient research evidence that can be used to persuade often reluctant administrators that they will help people achieve their desired outcomes. The second is that many mental health systems either do not have, or are unwilling to allocate, the required resources to adequately fund the full range of PSR interventions. Many mental health advocates believe that all should be available to people who need them.

Two striking examples are the need for smoking cessation and weight management programs. Despite the fact that smoking and weight gain are linked to several life threatening illnesses, many mental health systems do not provide the PSR components of the programs, instead offering only limited guidance or medication interventions. For people with serious mental illnesses this is particularly unhelpful because of the recently discovered neurobiologic links between tobacco use, schizophrenia, depression, and psychotropic medications (Dani & Harris, 2005; Williams & Ziedonis, 2004). Quitting

smoking for people with serious mental illnesses is very challenging and without specialized support, can be extremely difficult. Yet, programs that provide strong support coupled with medical interventions to quit smoking are not prevalent. Likewise, many anti-psychotic medications induce weight gain, very often leading to metabolic syndrome, a life threatening condition. Yet, like smoking cessation, many mental health systems do not provide early intervention aimed at helping avoid weight gain and all too often, do not provide intense weight management and follow up services.

Provision of the full range of PSR interventions requires a strong commitment to allocating sufficient resources for adequate and appropriately trained staff and a commitment to maintaining the interventions over the long term. This can be difficult for many mental health systems which are often under-resourced and may not have the capability to provide the services even if they very much want to.

## Summary

In addition to the underlying values and principles that are a pre-requisite for provision of any PSR service discussed in the first Interventions module, and to the EBPs discussed in the second Interventions module, there are a range of promising or emerging practices and supporting services that are generally regarded as highly useful for assisting people recover from the effects of serious mental illness and achieve their full functional capability. While these do not yet have sufficient evidence to consider them as EBPs, many practitioners and most consumers believe they are an essential component of a good recovery oriented mental health system.

All of the PSR interventions discussed in the Interventions modules, including those presented in this one, require adequate staff that are appropriately trained. They also generally require a commitment to continuing the intervention for considerable lengths of time (often 9 months or more, or for as long as the person needs the service) and these requirements are resource intensive. Many mental health systems either do not have sufficient funding to provide them or are unwilling to allocate adequate resources to provide them properly. This is a significant challenge for psychologists and other practitioners who want to offer the full armamentarium of PSR services and do so with the greatest possibility of success for people with serious mental illnesses.



## Sample Learning Activity

There are two parts to this exercise. For the first part, the large group is to be divided into two groups. Each group is to choose the one intervention from the promising practices and supporting services that the group believes to be the most valuable. Both groups cannot choose the same intervention. Each group is to make a comprehensive list of the components of the practice and determine how each of the components would be implemented in practice. This information will be used in the second part of the exercise.

For the second part of the exercise, a role play is to be devised by each group using the participants to play out how each of the components of the practice would look. The full group is then reconvened. One person is to play the part of a consumer who will comment at the end on how he or she felt about the intervention, its components, how impactful it would be, and how it could be made more helpful to his or her recovery. The full group is to discuss each of the role plays.

## Sample Evaluation Questions

### Question

### Correct Answer

1. Following are false statements and not a reason(s) for providing gender specific trauma services:

a) men often have difficulty expressing emotion and need separate services to help them deal with their feelings

b) women frequently have child care responsibilities that necessitate service provision at times that are outside regular working hours

c) the neurobiologic mechanisms of men and women are different due to differing hormonal levels and their ability to process information can be affected in emotionally laden situations

d) all of the above

d is correct

e) a and b above

f) none of the above

2. The slogan "Housing First" means:

a) stable housing should be offered to everyone with a serious mental illness before assessments are completed and before medications and other interventions are considered

b) people with lived experience consider housing to be the most important service of any that are available and the one they would choose above all others

c) both of the above

d) neither of the above

d is correct

3. A smoking cessation program should be provided as part of a comprehensive PSR service even though it may be available in Primary Care because:

a) neurobiologic interactions make it extremely difficult for people with schizophrenia and other serious mental illnesses to quit

b) the stigma people with serious mental illnesses experience may make it difficult to attend and be accepted by people without similar illnesses in a Primary Care clinic

c) because of the difficulty of quitting for people with serious mental illnesses, support from practitioners they are familiar with can be helpful

d) all of the above

d is correct

e) none of the above

True

False

4. Research on the efficacy of early psychosis intervention programs has

shown that the longer the delay in providing services after psychosis appears, the poorer the ultimate outcome T

5. People with lived experience of serious mental illnesses rarely value services they receive from their peers due to confidentiality issues and the lack of evidence supporting their efficacy F

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## Additional Resources

American Psychological Association Recovery to Practice Initiative.

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## Citing the Curriculum

Citation for this Module:

American Psychological Association & Jansen, M. A. (2012). Interventions III: Promising or Emerging Practices and Supporting Services. *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

Citation for the full Curriculum:

American Psychological Association & Jansen, M. A. (2014). *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

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# American Psychological Association

## Recovery to Practice Initiative Curriculum: Reframing Psychology for the Emerging Health Care Environment

### *10. The Forensic System and Related Issues I: Homelessness, Substance Abuse, Trauma, Gender, Race, and Culture*

**NOTE:** There are two Forensics modules. They are designed to be used together and are not intended to be used separately or as stand alone modules

August 2014

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## Overview

This is the first of two modules that consider issues related to people with serious mental illnesses in the forensic/criminal justice system. The two modules are designed to be used together; they cannot stand alone as the content of any one is not sufficient to understand the issues or provide recovery oriented psychosocial rehabilitation (PSR) interventions.

In this first Forensics module, information is presented about people with serious mental illness who are in the forensic/criminal justice system. People with serious mental illnesses who are in these systems are frequently homeless, have recently been homeless, and are at high risk of homelessness, have a high rate of co-occurring substance abuse disorders, and almost always have been exposed to or been the victims of trauma. All of these factors are related to, and impact on an individual's interaction with these systems, and have important implications for recovery and psychosocial rehabilitation efforts.

The second module in the Forensics series presents information about the interventions currently recommended to help people in the system avoid re-incarceration and achieve a stable and satisfying life in the community. Given the complexity of the issues involved, release planning and intervention efforts must also be complex and information about this critical component is also presented.

In both of the Forensic/Criminal Justice System modules, the terms forensic and criminal justice system are frequently used interchangeably. In some jurisdictions, the forensic system refers to inpatient settings while in others, it refers to the totality of the criminal justice system. In some settings, jails, prisons, mental health courts, jail diversion programs are considered to be part of the forensic system, while in others, they are called by a different system name. For clarity, in both of the Forensics modules, the terms are used interchangeably, although it is recognized that there are often critical distinctions within these systems.

It is important to note however, that forensic psychiatric hospitals and jails/prisons are very different. For the most part, forensic psychiatric hospitals provide at least minimal levels of treatment, i.e., psychotropic medications (sometimes over medicating individuals), traditional assessment, and varying kinds and levels of interventions. For the most part, jails and prisons, despite their status as the largest "warehouse" of individuals with mental health disorders, provide little to no treatment (although in rare cases, some jails/prisons have become designated mental health providers) and sometimes keep individuals (particularly those with disabilities of all kinds) in isolation, padded cells, etc., with no access to toilet facilities, fresh air, exercise, medication, or other essentials of human life, except for food passed through a small opening in the door.

While the deplorable conditions of jails and prisons may make forensic psychiatric hospitals appear to be stellar institutions, for the majority of U.S. jails, prisons, and forensic psychiatric hospitals, there are not adequate or appropriate services for people with serious mental illnesses in any setting. Though they are distinct, the Forensics modules in this

curriculum treat them similarly because of the paucity of literature on either category and because both have major hurdles to overcome in order to provide the services needed by people with serious mental health conditions.

## Learning Objectives

At the end of this module you will be able to:

- Identify four confounding factors most often experienced by people with serious mental illnesses who are incarcerated
- State the range of prevalence of co-occurring substance use disorders among those with serious mental illnesses who are incarcerated
- List four cultural reasons why individuals from minority racial communities and minority cultures may receive poor treatment in forensic settings
- Describe at least three reasons why exposure to trauma is considered the norm for people with serious mental illness who are in the forensic system
- Describe the four circumstances that vulnerable women with serious mental illness are at risk of encountering

## Resources

- Lecture Notes
- Required Readings
- Lecture Notes Citations
- Sample Learning Activity
- Sample Evaluation Questions
- Additional Resources

## Required Readings

Foulks, E. F. (2004). Commentary: Racial bias in diagnosis and medication of mentally ill minorities in prisons and communities. *The Journal of the American Academy of Psychiatry and the Law*, 32, 34–35.

Simpson, A. I. & Penney, S. R. (2011). The recovery paradigm in forensic mental health services. *Criminal Behaviour and Mental Health*, 21, 5, 299–306.

Substance Abuse and Mental Health Services Administration GAINS Center for Behavioral Health and Justice Transformation. (undated-a). *Creating a Trauma-Informed Criminal Justice System for Women: Why and How*. Available at:

<http://www.gainscenter.samhsa.gov/html/>

## Activities

Complete the following activities:

- Read the lecture notes
- Read the required readings
- Engage in a learning activity related to this module
- Evaluate students' understanding of this module.

## Lecture Notes

People with lived experience of serious mental illness are strongly encouraged to be part of the delivery of the curriculum including being active participants in the delivery of the lecture. Refer to the curriculum Instruction module for additional information.

### Introduction

People with serious mental illnesses who have become caught up in the forensic/criminal justice system face many challenges, and these challenges are frequently different from, or greater than, the challenges faced by people with similar illnesses who are not in the forensic/criminal justice system. A recent systematic review of studies looked at the prevalence and intersection of mental illness, homelessness, gender, victimization, and involvement with the justice system and found high consistency among the studies reviewed for the prevalence of these variables within a majority of the population. These authors noted the high levels of victimization in this population, especially among women which reinforces the need for gender specific trauma services for this population. These authors also noted the paucity of literature on victimization contrasted with the much greater literature on perpetration of crime, calling attention to the double stigma surrounding mental illness and involvement with the justice system. The high rates of contact with the criminal justice system among people with serious mental illnesses who are homeless also serves as a call for urgent attention to ensuring stable housing for this population. (Roy, Crocker, Nicholls, Latimer & Ayllon, 2014). These issues are discussed in greater detail in this module.

### Prevalence

The prevalence of people with serious mental illnesses in justice related settings is higher than their overall prevalence in the population with incarceration rates estimated to be about 20% (American Psychiatric Association, 2000). Cusack, Morrissey, Cuddeback, Prins & Williams (2010) summed the situation up as follows:

Recent estimates suggest that over one million people with serious mental illness (SMI) are booked into U.S. jails each year resulting in an overall prevalence rate of 15% for men and 31% for women (Steadman et al. 2009). In fact, the odds of a person with SMI being jailed are significantly greater than the odds of being hospitalized (Morrissey et al. 2007). Individuals displaying symptoms characteristic of mental illness were found to have a 67% higher probability of being arrested than individuals not displaying such symptoms (Teplin 1984, 2000). Moreover, after this initial arrest, individuals with SMI are more likely to be detained in jail (as opposed to released on own recognizance or have cases dismissed), and once jailed, stay incarcerated 2.5–8 times longer in comparison to their non-mentally ill counterparts (Council of State Governments, 2005, p. 356–357).



People with serious mental illness who are involved with the criminal justice system almost always have a multitude of co-occurring problems that confound their situation. Seventy five percent of those with serious mental illnesses have co-occurring substance use disorders, most are in poor physical health, many are homeless or at high risk of homelessness, most have a history of exposure to severe trauma, and more women and African American men with mental health disorders are incarcerated (Almquist & Dodd, 2009; American Psychiatric Association, 2000; Beck, Karberg & Harrison, 2002; Cusack, Morrissey, Cuddeback, Prins & Williams, 2010; Durose, 2003; Gunter, Arndt, Wenman, Allen, Loveless, Sieleni & Black, 2008; Harrison & Beck, 2002; Harrison & Karberg, 2003; Konrad, 2002; McNiel, Binder & Robinson, 2005; Peters, Bartoi & Sherman, 2008; Prins & Draper, 2009). These factors are further complicated by the fact that the offenses committed by ill people who are incarcerated range from petty crimes (sometimes committed to obtain money for drugs or deliberately to obtain shelter in jail), to very serious crimes such as murder, rape, severe assault and battery, arson, etc. Sometimes people with serious mental illnesses are picked up by police simply because their symptomatic behavior is mistaken for criminal activity.

## **The Forensic/Criminal Justice System and the Recovery Paradigm – A Conundrum**

In many ways, forensic/criminal justice settings are antithetical to the concept of recovery for people with serious mental illness. Individuals who are incarcerated or are in forensic settings have little free choice and often have serious threats to their own safety. Thus, in most of these settings, there is little ability to provide services consistent with the recovery paradigm and to offer services designed to help people learn the skills they need to achieve their life goals.

Forensic patients (referring particularly to those found unfit to stand trial, not criminally responsible, or with forensic hospital as the final disposition after criminal offending) have unique rehabilitative needs. Their recovery tasks encompass all of the usual elements including recovery from acute symptoms, finding medication that is effective and gaining insight into their illness and the need for treatment. They must try and define a 'life worth living' for themselves, overcome problems of functional impairment, find vocational support and foster healthy relationships with family and friends...The offender-patient, however, is likely to have additional tasks to do, over and above these 'typical' recovery tasks. The extra work would be related to the origins and effects of their offending, and the legal oversight and accountabilities now imposed upon them. Furthermore, these variables coalesce in the context of a secure hospital where the person is often isolated from community contacts and living within a structure of compulsory care that curtails liberty and several key elements of autonomous decision-making, such as consent to treatment or management of finances. (Simpson & Penney, 2011, p. 301-302).

Currently, in most components, though not all of the forensic or correctional system (jails, prison, forensic psychiatric hospitals, probation and parole settings), there is little real treatment and much emphasis on reducing risks (real or imagined) to the public. Respect, autonomy, person centered care, hope, evidence based practices (EBPs), etc. are currently not conceptualized as part of the system except by a relatively rare few, many of whom have written several excellent monographs about how to move forward. Given the increasing census of correctional systems around the country and the decreasing budgets allocated to these systems, implementing recovery oriented best practices remains a desirable but elusive goal. The picture that emerges is a complicated one where little treatment is all too often provided, coordinated release planning is rare, and re-incarceration is frequent, creating a revolving door of incarceration, mental and physical ill health, homelessness, substance abuse, and traumatic experiences.

## **Serious Mental Illness and the Forensic/Criminal Justice System: Homelessness, Substance Abuse, Trauma, Gender, Race, and Culture**

It is impossible to consider the problems of, and potential for helping people with serious mental illnesses in the forensic and criminal justice systems without considering the multitude of issues that are intertwined with and impact on, the individuals involved.

### **Homelessness**

While many mental health professionals are aware that people with serious mental illnesses are often homeless or at high risk of becoming homeless, the fact that many of these individuals also end up in the forensic/criminal justice system is less well recognized.

In a country where there is no jurisdiction where minimum wage earners can afford the lowest Fair Market Rent, and where rates of homelessness are rapidly growing, it is increasingly difficult to avoid jail as a substitute for housing (The National Coalition for the Homeless and the National Law Center on Homelessness & Poverty, 2002).

Since the closing of the large state mental hospitals in the mid to late 1960s and the failure of the community mental health movement largely due to inadequate funding, many people who would otherwise have been in the state hospitals find themselves living on the street and increasingly addicted to alcohol and or drugs. People who are homeless are often picked up for vagrancy, petty crimes, drunkenness or behavior resulting from drug use, or because they appear to be a danger to themselves or to others. In addition to being homeless, these individuals are often seriously ill, addicted, and most have experienced severe trauma (Folsom, Hawthorne & Lindamer, 2005; Greenberg & Rosenheck, 2008; Wenzel, Koegel & Gelberg, 2000).

As described in the Interventions III module in this curriculum:

Having a place to live is one of the most fundamental and important aspects of life. Yet, people with serious mental illnesses are often either homeless or at risk of

becoming homeless (Padgett, 2007). Many believe that having decent, stable, affordable housing of one's choice is the first step toward achieving recovery and most people prefer to live independently; for this reason the slogan "Housing First" has developed as one of the cornerstones of recovery services.

Research is currently underway to determine the benefits of providing housing before other services, especially for people with co-occurring disorders. Many studies have found decreased use of alcohol and drugs, reduced costs for police services, emergency room treatment, increased housing stability, and decreased psychiatric hospitalization when people have a stable place to live (Culhane, Metraux & Hadley, 2002; Gulcur, Stefancic, Shinn, Tsemberis, et al., 2003; Lipton, Siegel, Hannigan, Samuels & Baker, 2000; Pearson, Montgomery & Locke, 2009).

Providing supported housing is thought by many to be the key to helping people with serious mental illnesses remain out of jail and in the community but this often proves difficult due to the double stigma of serious mental illness and criminality and lack of resources for housing stock and personnel from the many disciplines needed for success.

### **Substance Abuse**

According to the Substance Abuse and Mental Health Services Administration's (SAMHSA) GAINS Center:

People with co-occurring mental health and substance abuse disorders are often excluded from treatment programs. Consequently many get caught up in the criminal justice system....In addition to a range of negative consequences (e.g., more frequent hospitalizations and higher suicide rates), co-occurring mental health and substance abuse disorders are also associated with poor social functioning, homelessness, violence, arrest, and incarceration. Criminal offenders with co-occurring disorders often display aggressive and violent behavior, have long histories of institutionalization, and exhibit a diminished ability to function independently in jail, prison, or community correction settings (undated-b, p. 2).

A very high proportion of those with serious mental illness who are incarcerated have co-occurring substance use disorders with estimates ranging from 50 to 78% (American Psychiatric Association, 2000; Gunter, Arndt, Wenman, Allen, Loveless, Sieleni & Black, 2008; McNiel, Binder & Robinson, 2005; Peters, Bartoi & Sherman, 2008; Prins & Draper, 2009). Because use of alcohol and other drugs can lead to risky health behaviors and criminal behavior, timely assessment and treatment are critical but unfortunately, this is not typically the case (Peters, Bartoi & Sherman, 2008). The chief reasons are that the criminal justice system is not well equipped to address the multiple needs of this population. The system does not have adequately trained mental health personnel, few specialized treatment programs exist in forensic settings, resources for proper transition planning and follow up are lacking, risk management is seen as the principal mandate, and like other social services the budget is cut repeatedly (Peters, Bartoi & Sherman, 2008; Prins & Draper,

2009). Partly due to these factors, those with co-occurring mental illness and substance use disorders who have been incarcerated continue to fall through the cracks, and continue using alcohol and other drugs. Those using drugs but not taking prescribed medication have been found to be responsible for more violent crimes, leading to the sensationalization of news stories about people with serious mental illnesses (McNiel, Binder & Robinson, 2005; Reuland, Schwarzfeld & Draper, 2009).

## Trauma

People with serious mental illnesses are more than twice as likely to be victims of violence than those without mental illness (Kooyman, Dean, Harvey & Walsh, 2007; Silver, 2002), and are more likely to be victims of violence than to be perpetrators of violence (Brekke, Prindle, Bae, et al., 2001). A large majority of people with serious mental illnesses who have been incarcerated have experienced trauma either before being incarcerated, during incarceration, or both (Kooyman, Dean, Harvey & Walsh, 2007). The rate of exposure to violence and the traumatic effect of this exposure is so high for people involved in the criminal justice system, and in particular for women, that most consider it the norm rather than the exception (Osher & Steadman, 2007). Once inside prison, both men and women with mental health disorders are also often subjected to physical violence and are more likely to be victims of violence than incarcerated persons without mental illnesses (Blitz, Wolff & Shi, 2008). Although less frequent, this can also be the case for those in forensic psychiatric hospitals.

The severity of the trauma experienced by the majority of those in the system was summarized by Jennings, 2008:

The kinds of trauma experienced by persons who are or who become recipients of public mental health services are usually not associated with “single blow” traumatic events (Terr, 1991) such as natural disasters, accidents, terrorist acts, or crimes occurring in adulthood such as rape and domestic violence (Giller, 1999). Rather, the traumatic experiences of adults, adolescents and children with the most serious mental health problems are interpersonal in nature, intentional, prolonged and repeated, occur in childhood and adolescence, and may extend over years of a person’s life. They include sexual abuse or incest, physical abuse, severe neglect, and serious emotional and psychological abuse...They are traumatized further by coercive interventions and unsafe psychiatric environments (Jennings, 1994; Cusack et al., 2003; Frueh et al., 2000; Frueh et al., 2005; Grubaugh et al., 2007; Robins et al., 2005) and at times sexual and physical abuse in inpatient or institutional settings, jails, and prisons (p. 2).

Because jails and prisons (and to a lesser extent forensic psychiatric hospitals) can be highly dangerous environments and particularly so for people with serious mental illnesses, individuals often develop adaptive behaviors that help them survive (Rotter, McQuiston, Broner & Steinbacher, 2005). Most treatment providers are unaware of the need for such

adaptation and the ensuing behavioral and attitudinal changes that these individuals must make to survive. The result is that providers see such behaviors as resistance, lack of motivation, pathology, or symptoms of the person's mental illness making communication and establishment of trust difficult, and impeding treatment provision and transition to successful community life. Mental health providers need to be educated about life in correctional facilities and need to understand the reasons why people adopt the attitudes and behaviors they need to survive in these frequently abusive situations. The effects of trauma are so severe that psychologists and other mental health providers must use extreme care to avoid re-traumatizing individuals.

Due to the deplorable conditions people with serious mental illness encounter in jails and prisons, severe traumatization occurs frequently.

All too often, seriously ill prisoners receive little or no meaningful treatment. They are neglected, accused of malingering, or are treated as disciplinary problems. Without the necessary care mentally ill prisoners suffer painful symptoms and their conditions can deteriorate. They are afflicted with delusions and hallucinations, debilitating fears, and extreme and uncontrollable mood swings. They huddle silently in their cells and mumble incoherently or yell incessantly. They refuse to obey orders or lash out without provocation. They assault other prisoners or staff. They beat their heads against cell walls, smear themselves with feces, self-mutilate, and commit suicide. Security staff typically view mentally ill prisoners who break rules and act out as difficult and disruptive. Whether as punishment or simply an administrative housing decision, officials often place them in barren high-security solitary confinement units. The lack of human interaction and the limited mental stimulus of twenty-four-hour-a-day life in small, sometimes windowless segregation cells, coupled with the absence of adequate mental health services, dramatically aggravate the suffering of the mentally ill. Some deteriorate so severely that they must be removed to hospitals for acute psychiatric care. But after being stabilized they are returned to the same segregation conditions, and the cycle of decompensation begins again.

The penal network is thus not only serving as a warehouse for the mentally ill, but, by relying on extremely restrictive housing for mentally ill prisoners, it is acting as an incubator for psychiatric breakdowns (Fellner, 2006).

According to Disability Rights Washington (2013):

People with mental illness, developmental disabilities, and traumatic brain injuries are being held in county jails from several weeks to months awaiting evaluation or restoration of their competency to stand trial.

In 2006, a national study by the Bureau of Jail Statistics found jail inmates with mental illness were twice as likely as those without to have been charged with facility rule violations (19% compared to 9%) (James & Glaze, 2006). The study further showed individuals in local jails with diagnosed mental health issues can be subject to sexual

or physical abuse by higher functioning inmates. Jail inmates who had a mental health issue (24%) were three times as likely as jail inmates without (8%) to report being physically or sexually abused in the past. As a result, individuals with mental health issues are more likely to be placed in segregation or have even more restrictions on their movement (Disability Rights Washington, 2013).

Traumatization of people with serious mental illnesses, and indeed people with disabilities of all kinds, is significantly increased when they are subjected to the conditions imposed on them by most jails and prisons in the US.

There are few if any forms of imprisonment that appear to produce so much psychological trauma and in which so many symptoms of psychopathology are manifested as isolation (Haney, 2003).

### **Women in the Forensic/Criminal Justice System**

For reasons that are not clear at present, the prevalence of women with serious mental illnesses is higher in forensic populations than that of men, typically estimated to be roughly twice as high at approximately 31 percent compared to 15 percent for men (Almquist & Dodd, 2009; Blitz, Wolff, Pan & Pogorzelski, 2005; Ditton, 1999; Sabol & Minton, 2008; Steadman, Osher, Robbins, Case & Samuels, 2009).

Due to their increased vulnerability, women with serious mental illnesses are at special risk for physical and sexual violence, trauma, risky sexual encounters, and incarceration (Ad Hoc Working Group on Women, Mental Health, Mental Illness and Addictions, 2006; Darves-Bornoz, Lemperiere, Degiovanni & Gaillard, 1995; Elklit & Shevlin, 2011). Compared to non-incarcerated women with mental health disorders in the forensic/criminal justice system, they have more symptoms related to addiction, anti-social personality disorder, and post traumatic stress disorder. Incarcerated women are more likely to have had traumatic experiences, including early sexual and physical abuse, than incarcerated men but equally likely to have substance abuse disorders (Lewis, 2006). For women with serious mental illness who are in contact with the justice system, severe abuse and trauma are considered the norm. For example, it has been found that 97% of homeless women with mental illness experienced severe physical and/or sexual abuse; 87% experienced this abuse both as children and as adults (Goodman, Dutton & Harris, 1997).

Treatment considerations, discussed in the second Forensics module, must be tailored to the special needs of women in the forensic/criminal justice system and trauma informed care must be a part of the mix of services.

### **Racial Factors in the Forensic/Criminal Justice System**

There are clear differences in the way that people of color are perceived and treated by criminal justice authorities and the forensic system in the U.S. These differences are confounded with social determinants of health, education, employment, housing, socio-

economic status, and other aspects of life in the U.S. (Primm, Vasquez, Mays, Sammons-Posey, McKnight-Eily, Presley-Cantrell, et al., 2010; Thompson, 2011).

African Americans are especially overrepresented in the forensic/criminal justice system, accounting for nearly half of all incarcerated individuals (U.S. Department of Health and Human Services, 2001). Moreover, African Americans are frequently labeled as criminals when they are actually suffering from serious mental illness, which may account for their overrepresentation in the system (Foulks, 2004). African Americans of all ages are also more likely to be the victims of serious violent crime than are Caucasians (U.S. Department of Health and Human Services, 2001). African American and Hispanic individuals who have a serious mental illness and are incarcerated also report higher rates of sexual victimization than white individuals with similar illnesses who are incarcerated (Wolff, Blitz & Shi, 2007).

People of color often leave the criminal justice system without having had an assessment or any treatment for their illness and without needed medications, funds to pay for living expenses, or referral to health services. As a result, many find themselves repeatedly recycling through the criminal justice system (Foulks, 2004).

### **Cultural Considerations**

There are many cultural factors that must be considered when an individual with serious mental illness interacts with the forensic/criminal justice system. Cultural factors may influence the responses an individual provides and the way in which law enforcement personnel and mental health professionals respond to and interact with the individual.

The impact of a person's cultural background can have profound effects on many areas of his or her life. Religion, beliefs about mental illness, its etiology, and its acceptability may influence the individual's willingness to speak with professionals about his or her life circumstances. The beliefs and values that a person is taught and grows up with can have considerable influence on the ways behavior is viewed, acceptability of seeking or accepting mental health services, the ability of women and young people to speak for themselves, establish goals, determine skills they wish to develop, etc. Language barriers have a profound effect on ability to communicate the many important facets of a person's life and background.

Due to language and cultural factors, immigrants and refugees may be at particular risk of ending up in the forensic/criminal justice system. When an immigrant or refugee does not speak the country's language and is influenced by cultural factors that deviate from the country's norm, and also has a serious mental illness, the consequences can be challenging for all involved. The vast majority of immigrants and refugees who need mental health services never receive them. It has been estimated that 92% of immigrants and refugees who need mental health services will not receive them (Birman, Ho, Pulley, Batia, et al., 2005; Ellis, Lincoln, Charney, Ford-Paz, et al., 2010; Kataoka, Zhang & Wells, 2002). Thus,

the likelihood of these individuals ending up in the forensic/criminal justice system can be quite high.

Some factors that should be considered when mental health providers encounter individuals in these settings include the following:

- The concept of mental illness is virtually non-existent in some cultures because behaviors are considered to be under the control of spirits or other forces that can be controlled by indigenous healers or faith based providers (Constantine, Myers, Kindaichi & Moore, 2004; Malarney, 2002). Even where mental illnesses are seen as true illnesses, stigma may be so great that seeking or accepting mental health services is extremely difficult if not impossible. Some cultures do not afford women the opportunity to express opinions or make decisions, reserving these for male members of the family (Said-Foqahaa, 2011), and making it very difficult for women in forensic and correctional settings to discuss aspects of their life.
- Another cultural issue that is not typically discussed involves trauma resulting from family perpetrated physical or sexual abuse. Some cultures consider women and children to be property to be used as desired (Chaudhuri, 2005; Said-Foqahaa, 2011), and in these cultures, abuse can be overlooked or even unofficially sanctioned. These situations lead to tremendous trauma for the victim and potentially for the perpetrator as well.
- Language barriers have a profound effect on one's ability to communicate the many important facets of a person's life and background that may have contributed, and may still contribute to the mental health problems experienced. In some languages, words or expressions used to describe aspects of mental illness do not exist. When combined with the stigma of behavioral problems, it can be extremely challenging to help people explain the problems they are experiencing and engage them in services.

A final issue that has become more apparent in the last decade concerns the detention of immigrants by U.S. Immigration and Customs Enforcement (ICE). According to recent reports, over 350,000 immigrants are detained each year. An unknown percentage of these have a serious mental illness and are taken into custody despite a criminal court finding that they should not be detained but require inpatient mental health treatment. In ICE detention centers, jails or prisons where they are often sent, these individuals frequently are not provided assessment or medication, receive little care and are often segregated in isolation, further exacerbating their mental illness (Venters & Keller, 2012). When added to the above mentioned problems faced by immigrants with serious mental illnesses, these individuals have little hope of achieving a successful transition to American life.

The experience of refugees deserves additional discussion. In addition to the multitude of problems experienced by immigrants and other newcomers, most refugees have endured extreme abuse at the hands of those in authority (Birman, Ho, Pulley, Batia, et al., 2005; Ellis, Miller, Baldwin & Abdi, 2011). As a result, refugees generally do not trust people in



authority or those who work in institutions or systems where the rules and procedures are determined by someone seen as having power. This is highly relevant and important for people who are detained in the forensic/criminal justice system. Refugees may experience extreme fear and perceive that they and their families are in imminent danger.

When all of these factors are combined (stigma from original background, language barriers, religious beliefs about the origin of mental illness, cultural beliefs or practices related to decision making and or sexual exploitation, trauma from abuse by those in authority) it should be clear that refugees may be at special risk for abuse within any component of the justice related system. Many of these same factors may also be true of non-refugees, i.e., those born in the U.S., but whose family members experienced discrimination and abuse at the hands of authorities. Some of these groups include African Americans, Native Americans, and other racial groups that experience discrimination which often continues to the present day.

Sensitivity to individuals from different backgrounds is essential if steps toward engaging an individual and his or her family are to be successful in the criminal justice/forensic system. Personnel who can speak multiple languages should be available and the cultural perspective of the person should always be respected.

## **Challenges**

It is difficult to imagine a group more stigmatized than those who have a serious mental illness and also have criminal involvement. For these individuals, obtaining appropriate treatment that is aimed at helping them identify and achieve their goals, become physically healthy, escape from homelessness and abuse, overcome substance abuse, overcome the devastating effects of trauma, and live a satisfying and productive life in the community are ideals that most will only dream about. The challenge for psychologists is to find ways to help individuals in this population overcome the double stigma and achieve these ideals.

Psychologists can confront this challenge by advocating for fundamental attitudinal change on the part of authorities who subscribe to a containment and risk management approach and by bringing their knowledge of mental health recovery to forensic and criminal justice settings. Despite the very real and substantial challenges faced by the forensic and criminal justice systems (lack of adequate funding, “dumping” of people with disabilities of all kinds into the criminal justice system, lack of access to appropriately trained mental health professionals, etc.), establishing a respectful environment where individual beliefs, values and goals are appreciated, and providing timely and appropriate treatment that is individualized for each person, would go a long way toward “rehabilitating” the forensic and criminal justice systems where so many people with serious mental illnesses find themselves.

## Summary

People with serious mental illnesses are more likely to be in the forensic/criminal justice system than those without such illnesses. The prevalence for African American men and women with serious mental illnesses is even higher than the prevalence for the seriously mentally ill population overall. Individuals who are in the forensic/criminal justice system are frequently homeless, have recently been homeless, or are at high risk of homelessness, have a high rate of co-occurring substance abuse disorders, and almost always have been exposed to or been, victims of trauma. Few receive adequate or appropriate treatment in jails and prisons and treatment oriented toward recovery and rehabilitation, while more often recognized as desirable, is rare in forensic psychiatric settings. As a result, many individuals with serious mental illnesses cycle through the system due to their co-morbid conditions of homelessness, substance use, abuse, physical ill health and criminal activity, some of which is deliberate to obtain shelter or is imagined by authorities who mistake symptoms of mental illness for criminal activity.

The forensic/criminal justice system is principally concerned with managing real or perceived risk to the public. For this reason, treatment of people in the system most often centers around a risk management or containment paradigm rather than a recovery oriented paradigm. Even mental health professionals who may desire to provide the most appropriate services possible, find that the system is rarely oriented to helping people identify and work toward goals they set for themselves.

Because of the double stigma of being seriously mentally ill and having a criminal history, individuals in most components of the justice system find it extremely difficult to exit from the cycle of incarceration, release, continued illness, inability to work, homelessness, substance abuse, and victimization and trauma and ultimately end up where the cycle began with re-incarceration. For women, people of color, and those with cultural differences such as immigrants and refugees, the situation can be even more dire, with extremely high rates of physical and sexual abuse, harassment, mis-diagnoses, and little if any treatment.

All of these factors come together to make the situation for an individual who has a serious mental illness and enters into the forensic/criminal justice system difficult to escape from without considerable effort on the part of the mental health professionals who must advocate for proper treatment for each person.

## Sample Learning Activity

The instructor should make up signs to be taped to participants' back with information describing individuals like those in the examples below. Participants should not be told what the characteristics are of each of the hypothetical individuals.

Each individual should have a sign taped on his or her back that describes a certain lived experience with either the mental health or criminal justice system. The hypothetical person's race/ethnicity/gender/disability/SES is also included in the short description. The following are examples; different or additional ones can be used if desired:

- a) A young African American male diagnosed with schizophrenia who exhibits bizarre behavior. Due to inability to find and keep work, he has committed a felony and is recently incarcerated;
- b) A white, working-class, middle-aged woman who is a war veteran diagnosed with PTSD who continues to be in a domestic violence situation while looking for work so that she can better support herself and leave her situation; she has been incarcerated for attempting to injure her domestic partner following abuse;
- c) A young South Asian lesbian immigrant woman who was working toward a green card through her company. She was recently diagnosed with cancer which required an amputation leaving her physically disabled and with chronic depression as a result of isolation and lack of affordable housing that is wheel-chair accessible in the city; she has taken to begging on the street and attempting to scam people for money.

Depending on the size of the group; people are broken up into small groups and interact with each other so that each individual can guess what the sign on their back says.

- 1) How long did it take for people to guess?
- 2) What did other people say in order for people to guess what was written on their back?
- 3) Discuss some of the internal conflicts that you had with the activity?
- 4) What are you going to do differently if you meet someone outside of the treatment setting in the community who has lived experience of serious mental health conditions and is in one of these situations?
- 5) What are you going to do differently in the treatment setting with people with serious mental health conditions so that you can work towards community integration following experience with the criminal justice /forensic system?
- 6) What are you going to do to change the systems in society that continue to perpetuate stigma?

# Sample Evaluation Questions

## Question

## Correct Answer

1. The prevalence of people with serious mental illnesses who are in the forensic system is:

a) about the same as the prevalence for people with such illnesses who are not part of the forensic system

b) estimated to be about 20% on average b is correct

c) roughly the same for women as the prevalence of people with similar illnesses who are not in the forensic system, but much higher for men with these illnesses

d) none of the above

2. The problems that co-occur with serious mental illnesses for people in the forensic system include:

a) substance abuse disorders

b) homelessness

c) abuse and traumatization

d) physical ill health

e) all of the above e is correct

f) a, c, and d above

## True

## False

3. Women with serious mental illness who have been abused and who become involved with the criminal justice system are treated fairly because the crimes they have committed are those that damage society's morality, i.e., prostitution, drug use, failure to care for their children, etc.

F

4. In the U.S., men from minority cultures, especially African American men with serious mental illnesses are often arrested for exhibiting symptoms of their illness when no crime has been committed

T

5. People who have experienced abuse rarely become severely traumatized because of their immune reaction that serves as a protective factor, i.e., becoming thick skinned, against further traumatization

F

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## **Additional Resources**

American Psychological Association Recovery to Practice Initiative.

<http://www.apa.org/pi/rtp>

Substance Abuse and Mental Health Services Administration GAINS Center for Behavioral Health and Justice Transformation. <http://www.gainscenter.samhsa.gov/html/>

## Citing the Curriculum

Citation for this Module:

American Psychological Association & Jansen, M. A. (2014). The Forensic System and Related Issues I: Homelessness, Substance Abuse, Trauma, Gender, Race, and Culture. *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

Citation for the full Curriculum:

American Psychological Association & Jansen, M. A. (2014). *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

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# American Psychological Association

## Recovery to Practice Initiative Curriculum: Reframing Psychology for the Emerging Health Care Environment

### *11. The Forensic System and Related Issues II: Interventions, Transition Planning, and Follow Up*

**NOTE:** There are two Forensics modules. They are designed to be used together and are not intended to be used separately or as stand alone modules

August 2014

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## Overview

This is the second of two modules that consider issues related to people with serious mental illnesses in the forensic/criminal justice system. The two modules are designed to be used together; they cannot stand alone as the content of any one is not sufficient to understand the issues or provide recovery oriented psychosocial rehabilitation (PSR) interventions.

In the first Forensics module, information was presented about the prevalence of people with serious mental illnesses who are in contact with the forensic/criminal justice system and about the many co-occurring factors that impact on the lives of the people involved. These factors include homelessness, co-occurring substance abuse, trauma and physical ill health.

This second module in the Forensics series presents information about the interventions recommended to help people avoid re-incarceration and achieve a stable and satisfying life in the community. Given the complexity of the issues involved, release planning and intervention efforts must also be complex and information about this critical component is also presented.

In both of the Forensic/Criminal Justice System modules, the terms forensic and criminal justice system are frequently used interchangeably. In some jurisdictions, the forensic system refers to inpatient settings while in others, it refers to the totality of the criminal justice system. In some settings, jails, prisons, mental health courts, jail diversion programs are considered to be part of the forensic system, while in others, they are called by a different system name. For clarity, in both of the Forensics modules, the terms are used interchangeably, although it is recognized that there are often critical distinctions within these systems.

It is important to note however, that forensic psychiatric hospitals and jails/prisons are very different. For the most part, forensic psychiatric hospitals provide at least minimal levels of treatment, i.e., psychotropic medications (sometimes over medicating individuals), traditional assessment, and varying kinds and levels of interventions. For the most part, jails and prisons, despite their status as the largest “warehouse” of individuals with mental health disorders, provide little to no treatment (although in rare cases, some jails/prisons have become designated mental health providers) and sometimes keep individuals (particularly those with disabilities of all kinds) in isolation, padded cells, etc., with no access to toilet facilities, fresh air, exercise, medication, or other essentials of human life, except for food passed through a small opening in the door.

While the deplorable conditions of jails and prisons may make forensic psychiatric hospitals appear to be stellar institutions, for the majority of U.S. jails, prisons, and forensic psychiatric hospitals, there are not adequate or appropriate services for people with serious mental illnesses in any setting. Though they are distinct, the Forensics modules in this curriculum treat them similarly because of the paucity of literature on either category and

because both have major hurdles to overcome in order to provide the services needed by people with serious mental health conditions.

## Learning Objectives

At the end of this module you will be able to:

- Identify four confounding factors most often experienced by people with serious mental illnesses who are in the forensic/criminal justice system
- State the two overarching findings for achieving community citizenship, e.g., chosen social and community roles, community tenure, economic self-sufficiency, etc.
- List the six interventions for people with serious mental illnesses in the forensic/criminal justice system that currently have good research support
- Describe four reasons why transition planning and follow up are essential
- Discuss nine of the essential elements critical to transition planning and follow up

## Resources

- Lecture Notes
- Required Readings
- Lecture Notes Citations
- Sample Learning Activity
- Sample Evaluation Questions
- Additional Resources

## Required Readings

Epperson, M., Wolff, N., Morgan, R., Fisher, W., Frueh, B. C. & Huening, J. (2011). *The Next Generation of Behavioral Health and Criminal Justice Interventions: Improving Outcomes by Improving Interventions*. New Brunswick, NJ: Rutgers University, Center for Behavioral Health Services & Criminal Justice Research.

Gannon, T. A. & Ward, T. (2014). Where has all the psychology gone? A critical review of evidence-based psychological practice in correctional settings. *Aggression and Violent Behavior*, 19, 4, 435-446.

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Osher, F., Steadman, H. J. & Barr, H. (2002). *A Best Practice Approach to Community Re-entry from Jails for Inmates with Co-occurring Disorders: The APIC Model*. Delmar, NY: The National GAINS Center.

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Substance Abuse and Mental Health Services Administration GAINS Center for Behavioral Health and Justice Transformation. (undated-a). *Treatment of People with Co-occurring Disorders in the Justice System*. Available at: [gainscenter.samhsa.gov/html](http://gainscenter.samhsa.gov/html)

Substance Abuse and Mental Health Services Administration GAINS Center for Behavioral Health and Justice Transformation. (undated-b). *Creating a Trauma-Informed Criminal Justice System for Women: Why & How*. Available at: [gainscenter.samhsa.gov/html](http://gainscenter.samhsa.gov/html)

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## Activities

Complete the following activities:

- Read the lecture notes
- Read the required readings
- Engage in a learning activity related to this module
- Evaluate students’ understanding of this module.

## Lecture Notes

People with lived experience of serious mental illness are strongly encouraged to be part of the delivery of the curriculum including being active participants in the delivery of the lecture. Refer to the curriculum Instruction module for additional information.

### Introduction

In the U.S. it is often said that jails and prisons have become the largest mental health treatment venue (McNiel, Binder & Robinson, 2005; Steadman, Osher, Robbins, Case & Samuels, 2009). However, little real treatment is provided in these settings and where any treatment is provided, it is most often psychotropic medication and little else. Moreover, when medication is provided, the prescribed dosage can be more than what might be prescribed in a non-criminal justice setting due to the focus on managing risk in these settings.

The reasons for the paucity of treatment are complex and relate to the double stigma of the illnesses and criminality, dwindling resources, and a corrections mentality that is often at odds with a treatment mentality. All of these make provision of effective services, especially those that are recovery oriented, challenging.

As discussed in the first Forensics module, forensic and criminal justice settings are antithetical to the concept of recovery for people with serious mental illness. Individuals who are in these systems have little free choice and often have serious threats to their own safety. Thus, in most, although not all, forensic/criminal justice settings, there is little recognition of, or ability to provide services consistent with the recovery paradigm and to offer services designed to help people learn the skills they need to achieve their life goals (Simpson & Penney, 2011). This is not always the case, and in many settings, mental health professionals are desirous of offering recovery oriented rehabilitation services. Due to the emphasis on risk management that is prevalent in most justice related systems, this is frequently not possible however.

Despite the fact that respect, autonomy, person centered care, hope, evidence based practices, etc. are currently not typically conceptualized as part of the forensic system/criminal justice system, there are some examples of forensic systems that have implemented recovery oriented services. Fulton State Hospital in Missouri has been a leader in these efforts (Newbill, Paul, Menditto, Springer & Mehta, 2011) and there are others where individual mental health professionals are desirous of doing so (Tapp, Warren, Fife-Schaw, Perkins & Moore, 2013).

Most mental health practitioners who work in forensic/criminal justice settings do not understand the adaptive behaviors that must be learned if one is to blend in, avoid abuse, and survive in an environment where coercion can come at the hand of other inmates and or at the hands of guards and officials – this is particularly true in jails and prisons. Mental health practitioners need to understand the complex dynamics of forensics/criminal justice

settings and assist the people they work with to learn healthy behaviors that will help them adapt in the community and avoid re-incarceration (Rotter, McQuiston, Broner & Steinbacher, 2005). Given the increasing census of correctional systems and the decreasing budgets allocated to these systems, implementing recovery oriented best practices remains a desirable but elusive goal for most.

Research on clinical interventions for people with serious mental illness in forensic settings has been limited, with much of that research aimed principally at reducing re-arrest, although some attention has been given to symptom improvement. In the forensic/criminal justice arena, there are several reasons for the limited research and the emphasis on reducing re-arrest, chief among them is the fact that those who have committed a crime have not been viewed as candidates for clinical services, largely due to the emphasis on risk management in these settings. This approach has been questioned more frequently in recent years due to the high cost of maintaining increasing numbers of individuals in expensive institutional settings, and because of the social implications of failing to help mentally ill offenders achieve a satisfying and productive life in the community. Research is also resource intensive and it can be difficult if not impossible for forensic systems that are continually facing budget cuts to choose between continuing to house people versus conducting research on the best ways to achieve long term solutions even though such long term solutions will ultimately benefit the systems and the people in them. Some have suggested a more collaborative approach, which includes asking the affected individuals what would best help them (Tapp, Warren, Fife-Schaw, Perkins & Moore, 2013); this collaborative approach is not normative however in the forensic/criminal justice system.

Among the more prominent endeavors has been research aimed at improving adaptive behavior deficits to help individuals learn more pro-social behaviors in order to integrate more successfully into the community. Social learning programs based on the work of Paul and Lentz (1977) are the basis for these efforts which have achieved success in multiple residential settings, including forensic psychiatric hospitals (Beck, Menditto, Baldwin, Angelone & Maddox, 1991; Lyskowski, Menditto & Csernansky, 2009; Newbill, Paul, Menditto, Springer & Mehta, 2011; Silverstein, Spaulding, Menditto, Savitz, Liberman, et al., 2009). Social learning programs aim to teach skill development, including communication and other social skills, increase an individual's capacity for self-care, and improve cognitive skills such as attentional capacity, problem-solving skills, etc., and help people learn more appropriate leisure skills (Newbill, Paul, Menditto, Springer & Mehta, 2011). While not common in forensic psychiatric hospitals, where provided, these programs have achieved remarkable success.

Like research, providing complex planning and intervention strategies is resource intensive. Unfortunately the forensic/criminal justice system is significantly under resourced and becoming ever more challenged by the growing census of people who are mentally ill, homeless, have co-occurring substance abuse disorders, are physically ill, and have been severely abused and traumatized. Thus, it is important to recognize that simply providing

one or more interventions will not solve the multitude of problems faced by individuals within this population. Rather, a set of services designed for, and with, the individual and tailored to his or her complex needs must be provided if we are to help people break the cycle of incarceration, release, symptom exacerbation, and re-incarceration (Epperson, Wolff, Morgan, Fisher, Frueh & Huening, 2011).

Driven often by intervention from the U.S. Department of Justice, but also by the independent recognition of a need to improve the quality of services provided, many state-run forensic psychiatric hospitals are further along in incorporation of recovery approaches and inclusion of a range of services than are prisons and jails. The kinds of treatments that can be found in modern, well-run forensic psychiatric hospitals (such as Fulton State Hospital in Missouri) include a range of treatments identified as effective, promising, and supporting, and are described in the Interventions modules of this curriculum.

Recently forensic and criminal justice mental health professionals have begun to think about using interventions already shown to be effective with non-forensic populations with those in forensic and criminal justice settings. A few of the evidence based practices (EBPs) discussed in the second interventions module of this curriculum (Interventions II) have been adapted and tested for this population as have some of the promising practices and supporting services discussed in Interventions III. Initial results indicate some success with some individuals. Results are not clear cut however, as there are several different settings within the overall forensic/criminal justice system, and because of the diversity of the population which ranges from people who have committed petty crimes to those who have committed capital offenses and also ranges from people with less serious mental health disorders to those with very severe mental illnesses. It can also be difficult to recruit subjects who are willing to participate in research studies; further there is a high drop out rate from such studies and from treatment. All of these factors make drawing consistent conclusions about the effectiveness of an intervention with varied populations difficult.

Notwithstanding the above, two overarching findings that have emerged consistently across settings and populations are the following:

1. Combining mental health interventions with forensic supervision is necessary to achieve success; often multiple interventions are needed.
2. The intensity of both the clinical intervention and the forensic supervision must be matched to the level of risk or recidivism of the individual with greater intensity afforded to those at higher risk. In the forensic/criminal justice literature, this is called the Risk-Needs-Responsivity principle (Andrews, Zinger, Hoge, Bonta, Gendreau & Cullen, 1990; Blackburn, 2004; Prins & Draper, 2009).

The Risk-Needs-Responsivity principle is widely accepted as the premier model for guiding assessment and treatment in forensic settings. A recent adaptation is the Good Lives Model which places greater emphasis on a strengths based approach (Barnao, 2013), but which does not differ substantially in content from the Risk-Needs-Responsivity principle

according to recent reviews (Andrews, Bonta & Wormith, 2011). However, from the perspective of providing services that are oriented toward helping people recover and achieve a satisfying and productive life in the community, some have called into question the ethics of following these models because of their reliance on controlling risk as the basis for providing services instead of focusing on establishing a true therapeutic partnership and providing the best services available (Gannon & Ward, 2014). Given the current emphasis on controlling real or perceived risk, the debate about what is most appropriate is likely to continue.

## **Interventions for People in Contact with the Forensic/Criminal Justice System**

Although intervention research related to these settings is limited, three clinical EBPs (assertive community treatment, cognitive behavioral therapy, concurrent disorders treatment (also known as integrated dual diagnosis treatment) and some promising/supporting practices (trauma informed care, supported housing) have been studied in forensic/criminal justice settings. Additionally, an intervention that includes mental health interventions and that was developed specifically to address individuals in the justice system (the mental health court) has been tested. These interventions are discussed below.

In addition, other interventions, most often based on cognitive behavioral approaches, are often offered in various justice related settings and some of these have begun to show positive results (Haddock, Barowclough, Shaw, Dunn, Novaco & Tarrier, 2009; Tew, Dixon, Harkins & Bennett, 2012). Systematic reviews of published studies have also begun to provide evidence that interventions to help people with serious mental illnesses in forensic systems can be beneficial (Duncan, Nicol, Ager & Dalgleish, 2006; Mancini, Linhorst, Menditto & Coleman, 2013; Martin, Dorken, Wamboldt & Wootten, 2012). For the most part, research on these efforts is in early stages. Consequently, the following discussion is limited to what is currently known about using the existing EBPs, promising and supporting services, and mental health courts, in forensic settings.

### **Forensic Assertive Community Treatment (FACT)**

FACT is a version of the EBP Assertive Community Treatment (ACT), modified for use in the forensic system. FACT combines mental health and criminal justice involvement through collaboration between the two systems and is described as follows:

Forensic Assertive Community Treatment (FACT) is distinguished from ACT in four ways: participants have criminal justice histories, preventing arrest and incarceration are explicit outcome goals, the majority of referrals come from criminal justice agencies, and supervised residential treatment is incorporated into the program (Prins & Draper, 2009, p. 27).

People with serious mental illnesses in the varied parts of the criminal justice/forensic system are very diverse. Because of this, FACT and other interventions are typically provided in a wide array of settings. In addition to use in community settings for individuals with serious mental illnesses released from the criminal justice system, FACT has been used in jail diversion programs and in prison re-entry programs. Recently, characteristics of individuals in these two settings have been found to be very different. Prison re-entry consumers are more likely to be older, male, have schizophrenia, and be in assisted living, while jail diversion consumers are more likely to be female, have mood and substance use disorders, be living independently, and have been physically and sexually abused. Given these differences, FACT and other intervention programs need to be tailored to meet the needs of the group they are to be serving. Services for older and more ill individuals likely need to focus on providing help with independent living skills while services for younger, less severely ill persons may need to be aimed at helping people achieve successful and stable transition to more normalized community life (Cuddeback, Wright & Bisig, 2013).

Outcome studies for FACT in a variety of settings have yielded mixed results but several have shown decreased recidivism, improved community treatment engagement, and reductions in overall spending (Cusack, Morrissey, Cuddeback, Prins & Williams, 2010; Lamberti, Deem, Weisman & LaDuke, 2011; Prins & Draper, 2009). FACT is currently considered to be a promising practice for helping people in the forensic system who serious mental illnesses avoid re-incarceration and remain in the community. The services and the intensity of those services need continued study to determine which combination works best for consumers with varying needs and in different settings.

### **Cognitive Behavioral Therapy (CBT)**

The research literature is replete with recommendations for use of interventions based on CBT with incarcerated individuals with mental illness and particularly for those with conduct disorders and antisocial personality disorder, principally aimed at controlling anger and reducing aggression (Novaco, 2013; Wilson, Gandolfi, Dudley, Thomas, Tapp & Moore, 2013). Recent research has also shown promise for helping individuals with schizophrenia achieve better interpersonal functioning (Williams, Ferrito & Tapp, 2014), and helping individuals reduce the impact of substance misuse (Morris & Moore, 2009). Additionally, medication and psychoeducation combined with CBT have been found to be beneficial (Tapp, Perkins, Warren, Fife-Schaw & Moore, 2013). A recent meta-analysis of the effectiveness of CBT for corrections populations concluded that its use can substantially decrease recidivism (Lipsey, Landenberger & Wilson, 2007). This review found that several factors were related to increased success including adequate training for the clinician providing the intervention, skills training targeted at specific problem behaviors, the risk level of the participants, the quality of the treatment implementation, and the presence of anger management strategies and interpersonal problem solving components.

One CBT program that was designed specifically for forensic populations has been extensively evaluated, the Reasoning and Rehabilitation CBT intervention program (Fabiano, Porporino & Robinson, 1990; Porporino & Fabiano, 2000). The program has been implemented in several countries including the United States, Canada, England, Wales, Scotland, each of the Scandinavian countries, Spain, the Canary Islands, Germany, Australia and New Zealand. The program has consistently demonstrated good results (Tong & Farrington, 2006; Young, Chick & Gudjonsson, 2010). Cognitive-behavioral programs for this population typically address attributes most related to criminal behavior and that may be most amenable to change. These include such factors as impulsivity, inability to control anger, violent behavior, maladaptive patterns of thinking, antisocial behaviors and attitudes, associations with pro-drug and antisocial peers, poor social skills, and drug use.

### **Concurrent Disorders Treatment (Integrated Dual Diagnosis Treatment)**

The rate of co-occurring substance abuse and mental health disorders among forensic/criminal justice populations is extremely high, estimated to be 72% of both males and females in the corrections system (Abram & Teplin, 1991) and it is widely acknowledged that integrated treatment must be a cornerstone of efforts to assist persons to remain out of prison and achieve success in the community (Osher & Steadman, 2007; Prins & Draper, 2009). Unfortunately, needed treatments are not readily available; this is also widely acknowledged.

The components of a concurrent treatment approach include psychotropic medication, Motivational Interviewing, and CBT interventions.

The U.S. National Institute on Drug Abuse (NIDA) recently issued a revised report based on the latest research entitled Principles of Drug Abuse Treatment for Criminal Justice Populations. Due to the very high rates of co-morbid mental health and substance abuse disorder in forensic psychiatric populations, these principles could guide the provision of services for this population. The principles articulated by NIDA include:

1. Drug addiction is a brain disease that affects behavior.
2. Recovery from drug addiction requires effective treatment, followed by management of the problem over time.
3. Treatment must last long enough to produce stable behavioral changes.
4. Assessment is the first step in treatment.
5. Tailoring services to fit the needs of the individual is an important part of effective drug abuse treatment for criminal justice populations.
6. Drug use during treatment should be carefully monitored.
7. Treatment should target factors that are associated with criminal behavior.

8. Criminal justice supervision should incorporate treatment planning for drug abusing offenders, and treatment providers should be aware of correctional supervision requirements.
9. Continuity of care is essential for drug abusers in re-entering the community.
10. A balance of rewards and sanctions encourages prosocial behavior and treatment participation.
11. Offenders with co-occurring drug abuse and mental health problems often require an integrated treatment approach.
12. Medications are an important part of treatment for many drug abusing offenders.
13. Treatment planning for drug abusing offenders who are living in or re-entering the community should include strategies to prevent and treat serious, chronic medical conditions, such as HIV/AIDS, hepatitis B and C, and tuberculosis (U.S. Department of Health and Human Services, 2012).

The SAMHSA GAINS Center's publication entitled Treatment of People with Co-occurring Disorders in the Justice System (undated-a) is an excellent document that succinctly outlines what providers need to do to help people with co-occurring disorders. These are:

- Engage the person and encourage commitment
- Take steps to ensure continuity of care from one setting to another
- Provide comprehensive services
- Provide on-going assessment and services tailored to the needs of each individual.

The document also outlines the key strategies needed:

- Provide integrated treatment for both the mental health disorder and the substance abuse disorder; both should be considered primary disorders and treated as such
- Design individual psychosocial and skills building interventions that are tailored to the needs and goals of each person
- Review all medications and ensure that appropriate ones are used. Inform each person about the complications that can be caused by use of alcohol and other drugs
- Ensure community connections that follow through with release planning for continuity
- Integrate therapy with self help groups and support (p. 3).

### **Trauma Informed Care**

The prevalence of exposure to trauma is so high for individuals in the criminal justice system that it should be considered the norm (Osher & Steadman, 2007). For both men and women who are under probation supervision, 39 percent of those with mental illnesses,



compared with 12 percent of people without mental illnesses, reported being abused before their arrest (Prins & Draper, 2009). This figure does not include individuals in jails, prisons, or forensic psychiatric hospitals. If all those in the forensic system were included, the figures would likely be much higher. As described by Jennings (2008, p. 2):

Many of the individuals ... have developed extreme coping strategies, in childhood, adolescence and as adults, to manage the impacts of overwhelming traumatic stress, including suicidality, substance abuse and addictions, self-harming behaviors such as cutting and burning, hallucinations, emotional numbing and dissociation, hypervigilance, somatization, aggression and rage, re-enactments such as abusive relationships, and serious health risk behaviors (Saakvitne et al., 2000; Dube et al., 2001; Felitti et al., 2002; Felitti, 1998; Hammersley, 2004; Sareen, 2005; CDC, 2005)...For the most part these individuals have never received screening, assessment or treatment for trauma. (Cusack, Frueh & Brady, 2004; Frueh et al., 2002; Mueser et al., 1998). The situation is similar for children in the mental health service system. Although many have histories of severe interpersonal violence and multiple adverse childhood experiences, recognition of the trauma underlying their behaviors and diagnoses typically does not occur (Hodas, 2006; Perrin et al, 2000).

And from Herman:

The betrayal and relational damage occurring when a child is repetitively abused and neglected sets up lifetime patterns of fear and mistrust which have enormous impacts on his or her ability to relate to others and to lead the kind of life he or she wants. Recovery cannot occur in isolation. It can take place only within the context of relationships characterized by belief in persuasion rather than coercion, ideas rather than force, and mutuality rather than authoritarian control—precisely the beliefs that were shattered by the original traumatic experiences (Herman, 1992, p. 22).

According to SAMHSA:

Trauma-specific treatment services are “interventions designed to address the specific behavioral, intrapsychic, and interpersonal consequences of exposure to sexual, physical, and prolonged emotional abuse” (Substance Abuse and Mental Health Services Administration, 2000).

Harris & Fallot (2001) described a trauma informed system as:

A “trauma-informed” system is one in which all components of a given service system have been reconsidered and evaluated in the light of a basic understanding of the role that violence plays in the lives of adults, children and adolescents and families or caregivers seeking mental health and addictions services (Harris & Fallot, 2001). A “trauma informed” system uses that understanding to design service systems that accommodate the vulnerabilities of trauma survivors and allows services to be delivered in a way that will avoid inadvertent retraumatization and will facilitate consumer participation in treatment. It also requires, to the extent possible, closely

knit collaborative relationships with other public sector service systems serving these clients and the local network of private practitioners with particular clinical expertise in “traumatology”.

In contrast, trauma specific services are described as:

“Trauma-specific” services are designed to treat the actual sequelae of sexual or physical abuse trauma. Examples of trauma-specific services include grounding techniques which help trauma survivors manage dissociative symptoms, desensitization therapies which help to render painful images more tolerable, and behavioral therapies which teach skills for the modulation of powerful emotions (Harris & FalLOT, 2001). Treatment programs designed specifically for survivors of childhood trauma are consistent on several points: the need for respect, information, connection, and hope for clients; the importance of recognizing the adaptive function of “symptoms;” and the need to work in a collaborative empowering way with survivors of abuse (Saakvitne, 2000).

Though interventions designed to assist people who have experienced trauma are not yet an EBP, there has been research to support the efficacy of some specially developed interventions in the justice system (Prins & Draper, 2009; Substance Abuse and Mental Health Services Administration GAINS Center for Behavioral Health and Justice Transformation, 2011).

A recent review of interventions for people with serious mental illness and severe trauma found that both cognitive behavioral treatment (combined with psycho-education about traumatic reactions most often referred to as PTSD, breathing retraining, and cognitive restructuring) (Mueser, Rosenberg, Xie, Jankowski, Bolton, Lu, et al., 2008) and exposure therapy (combined with group therapy focused on education, relaxation training and social skills building) (Frueh, Grubaugh, Cusack, Kimble, Elhai & Knapp, 2009) were found to be effective, with the cognitive behavioral treatment program evaluated in the largest clinical trial conducted to date. This comprehensive review notes that continuing research is needed to address the extremely important but often overlooked issue of addressing trauma experienced by people with serious mental illnesses (Grubaugh, Zinzow, Paul, Egede & Frueh, 2011).

Elements common to many treatment modalities for PTSD include education, exposure, exploration of feelings and beliefs, and coping-skills training. CBT is common to many of the treatment paradigms. Components of these paradigms are listed in the excerpt below, taken from the website of the U.S. National Center for PTSD:

Cognitive-behavioral therapy (CBT) involves working with cognitions to change emotions, thoughts, and behaviors. Exposure therapy is one form of CBT that is unique to trauma treatment. It uses careful, repeated, detailed imagining of the trauma (exposure) in a safe, controlled context to help the survivor face and gain control of the fear and distress that was overwhelming during the trauma. In some

cases, trauma memories or reminders can be confronted all at once ("flooding"). For other individuals or traumas, it is preferable to work up to the most severe trauma gradually by using relaxation techniques and by starting with less upsetting life stresses or by taking the trauma one piece at a time ("desensitization") (www.ncptsd.va.gov).

Along with exposure, CBT for trauma includes:

- Learning skills for coping with anxiety (such as breathing retraining or biofeedback) and negative thoughts (cognitive restructuring)
- Managing anger
- Preparing for stress reactions (stress inoculation)
- Handling future trauma symptoms
- Addressing urges to use alcohol or drugs when trauma symptoms occur (relapse prevention), and
- Communicating and relating effectively with people (social skills or marital therapy).

One program that has several versions and has been tested with various populations including individuals in the forensic system with good initial results is Seeking Safety (Najavits, 2009). For more in-depth information about trauma interventions see the module in this curriculum entitled Interventions III.

#### *Trauma Informed Care for Women*

Several studies have reported the extremely high rates of abuse for women in the forensic/criminal justice system. The traumatic experiences of women put them at heightened risk for PTSD and other anxiety disorders with 34 percent meeting criteria for PTSD (Alvarado, 2002). The U.S. Bureau of Justice Statistics found that 73% of the women in state prisons and 75% of women in local jails have symptoms of mental disorders, compared to 12% of women in the general population. Three-quarters of the women who had a mental health problem also met criteria for substance abuse or dependence (James & Glaze, 2006).

The issue of services for women in the forensic system deserves special attention. It has been estimated that the likelihood of a woman entering the criminal justice system with a substance use disorder is 9 times the rate for women in the community and up to 48 times the rate for non-Hispanic white women aged 26 – 50 in the community (Teplin, Abram & McClelland, 1996). While these data are not specific to women with serious mental illnesses, it may be that the extraordinarily high rate of substance abuse among women in the forensic/criminal justice system is the result of their attempt to erase the memories and pain of physical and sexual abuse.

Women with mental health problems who do not receive appropriate mental health treatment while in the forensic/criminal justice system are highly vulnerable and at high risk for homelessness, violence, further abuse and trauma, and repeated involvement in the criminal justice system when they are released (Smith, Simonian & Yarussi, 2006).

Because most of the trauma experienced by women has been at the hands of men, women with a history of abuse by men will be unable to work through those issues in a mixed group; a mixed trauma group can actually exacerbate their trauma making gender specific interventions developed for women essential. Trauma treatment should be designed to provide a safe and secure environment where trust can be developed. Interventions designed to help women deal with the effects of trauma should be offered by trained women clinicians and in women-only groups. The Seeking Safety program mentioned above has been adapted for women in prison settings and has demonstrated sustained benefits for this population (Lynch, Heath, Matthews & Cepeda, 2012; Zlotnick, Johnson & Najavits, 2009).

### **Supported Housing**

Many of those with serious mental health disorders often have no place to live when they are discharged. These individuals, most of whom have also experienced trauma and may have been re-traumatized by the criminal justice experience, find themselves living on the streets and at risk of being re-traumatized, continued abuse of alcohol and other drugs, and re-incarceration. Supported housing, which is typically offered in conjunction with FACT, has been suggested as an approach that may be beneficial for helping these individuals to become connected with the treatment system and remain out of the forensic/criminal justice system.

Some studies have found that supported housing can improve outcomes for this population by helping people connect with treatment services that can lead to reduced incarceration rates (Culhane, Metreaux & Hadley, 2002; Osher & Steadman, 2007; Prins & Draper, 2009). Clearly, individuals need stable housing and having a safe and secure place to live coupled with help to remain connected with treatment services makes sense. All too often, resources to provide supported housing, FACT and other needed services are limited, making it difficult for people with serious mental illnesses who have been in the forensic/criminal justice system to achieve stability and a satisfying life in the community (Prins & Osher, 2009).

### **Mental Health Courts**

Mental health courts have been introduced in several jurisdictions throughout the U.S. and in Canada. Mental health courts are specialized court dockets that deal exclusively with people with mental health disorders in the criminal justice system. These courts combine community treatment services for people with serious mental illness with criminal justice supervision and have the following goals:

...to improve public safety by reducing criminal recidivism; to improve the quality of life of people with mental illnesses and increase their participation in effective treatment; and to reduce court - and corrections-related costs through administrative efficiencies and often by providing an alternative to incarceration (Almquist & Dodd, 2009, p. v).

Mental health courts are used for individuals who can be adjudicated to community supervision. The combination of criminal justice supervision with community treatment holds promise of helping individuals with serious mental illnesses avoid incarceration, increase community tenure and achieve stability. Almquist & Dodd, 2009, offered the following related to mental health courts:

Research has found that participants in some mental health courts have lower rates of recidivism than individuals with mental illnesses processed through the traditional criminal court system. Some research findings indicate that this trend continues after individuals are no longer under court supervision. Mental health courts have also been found to connect participants with mental health treatment services more effectively than do the traditional court system and jails. In addition, mental health courts have the potential to save money through reduced recidivism and associated savings in jail and court costs. Also, treatment costs are reduced by avoiding expensive inpatient care (p. vi).

Although chiefly a criminal justice intervention for individuals who are not incarcerated, the principle of coordinated care that mental health courts embody is one that the mental health service delivery system has been advocating for years. Combined with a range of interventions provided at the intensity needed by this population, and when implemented with competent and knowledgeable court outreach personnel who assist individuals to access needed health mental health, and legal services, it may be that mental health courts hold promise of helping individuals remain out of the forensic/criminal justice system and achieve a stable and satisfying life in the community (Sylvestre, Aubry, Smith & Bridger, 2010).

It must be noted however, that factors such as community isolation, social disadvantage, poverty and stigmatization will impede the success of interventions aimed at helping individuals achieve successful re-integration into the community. A wide range of interventions aimed at ensuring proper housing, successful employment if the person is able to work, help with medical and mental health follow up, and community integration that diminishes stigmatization are all necessary to help individuals in this population succeed (Barrenger & Draine, 2013).

## Transition Planning and Follow-up for Incarcerated People with Serious Mental Health Disorders

For people who are being discharged from forensic and criminal justice settings, providing adequate and appropriate transition planning and follow up are crucial (Cuddeback, Wright & Bisig, 2013). The failure to provide the needed planning and follow up is a major reason for the revolving door of release, illness, substance use, homelessness, trauma, and re-incarceration that afflicts this population.

Almost all jail inmates with co-occurring mental illness and substance use disorders will leave correctional settings and return to the community. Inadequate transition planning puts people with co-occurring disorders who enter jail in a state of crisis back on the streets in the middle of the same crisis. The outcomes of inadequate transition planning include the compromise of public safety, an increased incidence of psychiatric symptoms, relapse to substance abuse, hospitalization, suicide, homelessness, and re-arrest (Osher, Steadman & Barr, 2002, p. 1)...Inadequate transition planning puts people with co-occurring disorders who entered the jail in a state of crisis back on the streets in the middle of the same crisis (p. 3).

A comprehensive model to address the problem and provide guidance for how to ensure that coordinated and integrated planning and follow up services are delivered has been developed and is called the APIC model (Osher, Steadman & Barr, 2002). The model consists of the following components:

- Assessment of the person's clinical and social needs, and public safety risks
- Planning for the treatment and services required to address the person's needs
- Identifying required community and correctional programs responsible for post-release services
- Coordinating the transition plan to ensure implementation and avoid gaps in care with community-based services.

The authors stress that planning must take the following into account:

- The period immediately after release is critical – the first hour, day or week can determine success or failure and high intensity interventions that support the person during this time are essential;
- The person him or herself must be engaged and asked what helped or hindered success following previous incarcerations – this is considered the most important part of the assessment and planning process;
- Seeking input from family members;
- Addressing housing and the other multiple needs of the person;

- Naming specific community referrals that are appropriate for the person's medical, mental health, social and economic needs and forwarding a copy of the person's discharge summary to the community provider;
- Connecting the person with appropriate medical resources and making needed appointments;
- Ensuring that the person has an adequate supply of appropriate medication that will last until the first follow up appointment;
- Initiating applications for needed benefits (Medicaid, SSDI/SSI, veterans benefits, food stamps, Temporary Assistance for Needy Families (TANF), etc.
- Ensuring that the person has:
  - Adequate clothing
  - Resources to obtain adequate nutrition
  - Transportation from jail to place of residence and from residence to appointments
  - A plan for childcare if needed that will allow him or her to keep appointments (Osher, Steadman & Barr, 2002, p. 8–9).

Transition planning must attend to the cultural, racial, gender and age related factors that are important to ensure the person is linked to services that are accepting and compatible (Hicks, 2004; Osher, Steadman & Barr, 2002; Rotter, McQuiston, Broner & Steinbacher, 2005).

To ensure the person has as much support as needed to follow through with services, it is crucial to explicitly inform the person him or herself, the family, those in the releasing facility and the treatment providers in the community of the names and contact information for the person(s) responsible for following up between the time of release and the first follow-up appointment. On-going support is essential, as is a mechanism to stay in touch with the individual and reach those who miss the first follow-up appointment to re-schedule and get the person back on track with the transition (Osher, Steadman & Barr, 2002). Connecting people with their communities and ensuring that follow-up and help with all needed aspects (housing, employment, medical and mental health services, normalized leisure and socialization to diminish stigma, etc.) is essential (Barrenger & Draine, 2013).

## Challenges

The challenges facing psychologists and others desirous of finding and implementing interventions that help people with serious mental illnesses in the forensic/criminal justice system achieve their goals and live a satisfying life in the community include little research to guide decisions, few resources to undertake the studies needed and to implement recommended interventions, stigma and resistance to the concept of recovery and

rehabilitation for this population, an over emphasis on controlling risk, and the complexity of the problems individuals face.

In order to overcome these challenges, psychologists must be willing to partner with colleagues in the justice system to leverage resources and establish joint working relationships in order to provide the coordinated supervision and clinical interventions that are crucial to help people with serious mental illnesses overcome the multiple issues they face and achieve stability in the community. Leveraged resources and joint working partnerships can also help psychologists develop and carry out needed research to identify which interventions can be of most benefit for individuals in this population and under which conditions the greatest success can be achieved. Factors such as severity of trauma experienced, differential diagnoses, degree of symptomatology, degree of behavioral adaptation to the corrections environment, motivation for change, etc., are all factors that may impact on outcomes for this population – a group that is greatly in need of effective interventions to assist them to live well in the community and avoid re-incarceration.

Due to the deplorable conditions that people with mental health disorders (and disabilities of all kinds) find themselves in when it comes to jails, prisons, and to a much lesser extent forensic psychiatric hospitals, psychologists have an ethical responsibility to advocate for fundamental attitudinal change on the part of authorities who subscribe to a containment and risk management approach and to bring their knowledge of mental health recovery to forensic and criminal justice settings. Psychologists excel at finding research opportunities, obtaining funding to test promising practices in new settings, and translating the results of research into clinical practice. There are few populations more in need of this expertise than people in forensic and criminal justice settings and few institutions more worthy of utilizing this expertise of psychologists than those of the justice system.

## Summary

Despite the overwhelming numbers of people with serious mental illnesses in forensic and criminal justice settings, little real treatment is too often the norm, especially in jails and prisons. There are some noteworthy exceptions and mental health professionals are often desirous of providing recovery oriented rehabilitation services. In some institutions important research and clinical work is underway. However, lack of resources and a prevailing emphasis on risk management typically make this difficult to achieve in many settings.

Despite these challenges, some interventions have shown promise and several are recommended for people with serious mental illnesses in forensic/criminal justice settings including forensic assertive community treatment, cognitive behavioral therapy, concurrent disorders treatment, trauma informed care, and supported housing. Mental health courts, a specialized court docket dedicated to cases involving people with mental health disorders, combines forensic supervision with mental health interventions and has shown good results. Two principles have emerged from the forensic and clinical literature: combined



forensic supervision and mental health treatment are necessary, and the intensity of both the supervision and clinical interventions must be matched to the needs of the individual.

For individuals who are in the justice system, transition planning and follow up are crucial to avoid the revolving door that so many people with serious mental illnesses face. If released without a solid transition plan for stable housing, medical care, community intervention, establishing support and friendships, skills training tailored to each person's needs and wishes, and without intense supervision and continued follow-up, most will end up on the streets, abusing drugs, the victims of abuse, and ultimately re-incarcerated.

## Sample Learning Activity

For this activity, the large group can remain together as one group unless it is a very large group, in which case it can be divided into two groups. The activity has two parts. Each part has a discussion component following the activity.

Part 1. The first part is a round robin where everyone is to finish the sentence by filling in the blank following each word. The sentence with each word to be completed is:

Someone with serious mental illness who has been physically or sexually abused is picked up by the police and:

feels\_\_\_\_\_

is\_\_\_\_\_

wants\_\_\_\_\_

wishes\_\_\_\_\_

After each person in the group has taken a turn at filling in the remainder of the sentence after each word, the group is to ask each other questions about why the person gave each response, and discuss what alternate responses might be. The discussion should be based on what was learned from the content of this module.

Part 2. The second part of the activity consists of a group discussion about what each person thinks is the most important thing he or she could do for an individual with serious mental illness in the forensic system. Each person is to give one response. When all have given one response, the group is to discuss the responses and individuals should indicate why they agree or disagree with others' responses.

## Sample Evaluation Questions

### Question

### Correct Answer

1. The two overarching findings from forensic and mental health research are:

- a) the population is extremely varied and results are inclusive
- b) subjects are difficult to recruit and drop out frequently
- c) forensic supervision and mental health treatment are essential and both must be matched to the individual level of risk and need
- d) a and b above
- e) c above
- f) none of the above

e is correct

2. Thus far, three evidence based practices and some promising and supporting practices have been studied with this population and initial results are promising. These practices are:

- a) forensic assertive community treatment, cognitive behavioral therapy, illness management and support, supported education, trauma informed care, and supported housing
- b) integrated dual diagnosis treatment, cognitive behavioral therapy, forensic assertive community treatment, trauma informed care, supported housing, and mental health courts
- c) integrated dual diagnosis treatment, cognitive behavioral therapy, forensic assertive community treatment, family psychoeducation, supported employment, and mental health courts
- d) none of the above

b is correct

3. The single most important thing that can be done in transition planning is:

- a) working with the person to be released and asking him or her what he or she believes is most important to ensure success and if released previously, what did and did not work the last time
- b) engaging the support of family and friends so that help and support are available and to be sure that a support system is in place
- c) ensuring that the person has an adequate supply of medication
- d) connecting the person with community resources who will provide the services needed to avoid re-incarceration
- e) all of the above

a is correct

True

False

4. If transition planning is done correctly, following up with those who have been released from incarceration is not needed because community service agencies take charge of people once they are in the community

F

5. Transition planning must take into account the culture, gender, and race of those who are being released in order to ensure that the services the person is to be connected with are compatible, accepting of the person, and willing to work with the individual from his or her frame of reference

T

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## Additional Resources

American Psychological Association Recovery to Practice Initiative.

<http://www.apa.org/pi/rtp>

Substance Abuse and Mental Health Services Administration GAINS Center for Behavioral Health and Justice Transformation. <http://www.gainscenter.samhsa.gov/html/>

## Citing the Curriculum

Citation for this Module:

American Psychological Association & Jansen, M. A. (2014). The Forensic System and Related Issues II: Interventions, Transition Planning, and Follow Up. *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

Citation for the full Curriculum:

American Psychological Association & Jansen, M. A. (2014). *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

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# American Psychological Association

## Recovery to Practice Initiative Curriculum: Reframing Psychology for the Emerging Health Care Environment

### *12. Community Inclusion*

August 2014

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## Overview

In this module we will discuss the importance of including people with serious mental illness in all aspects of community and society.

## Learning Objectives

At the end of this module you will be able to:

- Describe two points related to the concept of social inclusion and discuss their relevance to recovery from serious mental illness
- Identify at least three intrinsic and extrinsic sources of stigma
- Discuss ten domains of participation that all individuals with or without serious mental illness should be included in to be full community participants
- Describe at least three effects of being excluded either intentionally or unintentionally, and discuss the downward spiral of marginalization

## Resources

- Lecture Notes
- Required Readings
- Lecture Notes Citations
- Sample Learning Activity
- Sample Evaluation Questions
- Additional Resources

## Required Reading

Office of the Deputy Prime Minister. (2004). *Mental Health and Social Exclusion*. London, England: Social Exclusion Unit. Document copyrighted by the Crown and used with permission. Available at <http://www.socialfirmsuk.co.uk/resources/library/mental-health-and-social-exclusion-social-exclusion-unit-report>

## Activities

Complete the following activities:

- Read the lecture notes
- Read the required readings
- Engage in a learning activity related to this module
- Evaluate students' understanding of this module.

## Lecture Notes

People with lived experience of serious mental illness are strongly encouraged to be part of the delivery of the curriculum including being active participants in the delivery of the lecture. Refer to the curriculum Instruction module for additional information.

### Introduction

This module provides an overview of community inclusion, also referred to as social inclusion, and discusses the implications of inclusion versus exclusion for people who are recovering from serious mental illness.

Community inclusion, or social inclusion, implies the integration of an individual or group into the community in which that person or group resides. Further, integration implies communication between and among the individual and others in the community, and also implies participation of the person in the activities of the community at large. Inclusion is the opposite of exclusion at all levels, but inclusion is often not the experience of people with serious mental illness. Intuitively, it would make sense that feeling accepted and included would have positive effects on one's mental status (Keleher & Armstrong, 2005).

Social exclusion is linked to poverty and deprivation. Poverty is consistently mentioned as a key cause and also a product of social exclusion. The effects of poverty on health status are well established (US Government Accountability Office, 2007). Unfortunately, it is well known that people with serious mental illnesses are some of the poorest and most vulnerable in our society. The cycle of exclusion, poverty, leading to lessened opportunities, further poverty and exclusion, is very difficult to break, especially without assistance from those in the community with the resources and power to effect change. The experience of social inequality and the stress associated with dealing with exclusion can have pronounced psychological effects and impact negatively on physical health status as well. People who are isolated from community and friends and lack social supports, tend to have more physical health problems. Racial and ethnic differences in health status also tend to reflect differences in social and economic conditions (Braveman, Egerter, An & Williams, 2009; Raphael, 2001).

Why are people excluded or made to feel unwelcome? One obvious reason is stigma. The effects of stigma are far reaching and have devastating consequences for those stigmatized, including poorer mental health and internalized stigma, referred to as self-stigma (Corrigan, Morris, Michaels, Rafacz & Rüsch, 2012). People who are stigmatized have reduced opportunities for community inclusion and participation (Corrigan, Green, Lundin, et al., 2001; Lauber, Nordt, Falcatto, et al., 2004; Mueller, Nordt, Lauber, et al., 2006). Stigma and discrimination are reflecting images that increase together and the effects of both are insidious. Creating opportunities for people with and without serious mental illnesses to meet and interact has been shown to break down stereotypes and reduce stigma (Vaughan & Hansen, 2004). This has been found to be especially true with respect to



reducing stigma due to perceived dangerousness, fear and social distance (Couture & Penn, 2003).

The stigma and discrimination that accompanies serious mental illness comes from several sources, some of which are intrinsic and some of which are extrinsic. Intrinsic sources include those coming from the person such as odd behaviors, poor hygiene, fear of rejection, discomfort that occurs when around others, etc. Extrinsic factors that lead to stigma include media portrayals of people with serious mental illness as dangerous, a mental health treatment system that often knowingly or unknowingly encourages segregation and stigma, community members who influence others to exclude individuals with serious mental illness, community rules about acceptable behaviors, and a general unwillingness to accept anyone who seems a bit different.

Efforts to reduce stigma have been undertaken in many parts of the world, but people with serious mental illnesses continue to be highly stigmatized, especially when exhibiting, or known to exhibit behaviors associated with psychosis. A major contributor has been the media which often highlights actions carried out by individuals thought to have a mental health disorder. Recently, media personnel have become more aware of this skewed reporting and some have made efforts to be more factual and even-handed in their reporting. A recent international conference devoted to examining stigma and looking at ways to overcome its effects published the following conclusions:

# Together Against Stigma: Changing How We See Mental Illness - A Report on the 5th International Stigma Conference

## Conclusions

Out of the enormous volume of content covered during the conference, a number of observations and key messages repeatedly emerged. Among the most prominent were:

1. **Including people with lived experience** (those with mental health problems and illnesses and their family members) is **critically important** when designing services, developing and delivering solutions and executing programs to combat stigma. "Nothing about us without us" was an oft-recited mantra.
2. **Contact-based education** (facilitating interactions between those with lived experience and groups that might hold stigmatizing attitudes) is highly effective in reducing stigma. Contact-based encounters can be both live and electronic, such as video.
3. **We must go beyond changing attitudes and seek to change behaviour** to effect real change where stigma is concerned. Behavioural changes should be measured.
4. **A need for greater research** into understanding how—and to what degree—stigma affects help-seeking among those with mental health problems.
5. **Working with the media** to raise awareness of mental health issues and establish best practices for reporting and for depicting mental illness is an effective approach with potential to have a positive impact on public perceptions.
6. **Engagement in creative arts** not only facilitates recovery but may also help break down barriers and reduce stigma.
7. **Programs must be tailored to specific audiences** in consideration of culture and context to achieve optimal outcomes. One-size-fits-all approaches are less effective.
8. **Prejudice and discrimination are prevalent within the health system** and must be recognized as such. Programs are needed to address this—from better mental health education at post-secondary institutions to contact-based initiatives in the field.
9. **Youth are an essential audience** to reach through anti-stigma programs, as mental health issues often first present in the teenage years. Dispelling stigma will encourage help-seeking and foster hope and confidence in recovery.
10. **Work plays an important role** in establishing a sense of worth, purpose and social inclusion. Work opportunities for persons with mental illness have to be fostered and the workplace and capitalized on as an environment for anti-stigma intervention.
11. **We must adopt a human rights and social justice framework** to bring about structural changes and support those living with mental illness—ensuring that individuals retain their rights and freedoms, and are able to exercise them (with support during periods when they cannot).

*Source: Mental Health Commission of Canada, Canadian Human Rights Commission, World Psychiatric Association Scientific Section on Stigma and Mental Health & Public Health Agency of Canada, 2012.*

Interestingly, studies from the World Health Organization (WHO) have shown that people with serious mental illnesses who live in developing countries where they are more readily accepted as part of the community may fare considerably better than their developed country counterparts. This conclusion has been discussed at length in the literature (Harrison, Hopper, Craig, et al., 2001; Hopper, Harrison, Janca & Sartorius, 2007; Jablensky, Sartorius, Cooper, Anker, et al., 1994; Jablensky, Sartorius, Ernberg, et al., 1992; World Health Organization, 1973; World Health Organization, 1979). The WHO work has been highly referenced and in the latest available publication, the authors stated:

The study demonstrated clearly a diversity of outcomes but “did not identify any particular pattern in the course and outcome of schizophrenic illnesses which could be

regarded as specific to a given area or culture.” The outcome of patients in the developing countries was not *uniformly* better, as compared to the outcome in developed countries. While high rates of complete clinical remission were significantly more common in developing country areas (37%) than in developed countries (15.5%), the proportions of continuous unremitting illness (11.1% and 17.4%) did not differ significantly across the 2 types of setting. Patients in developing countries experienced significantly longer periods of unimpaired functioning in the community, although only 16% of them were on continuous antipsychotic medication (compared with 61% in the developed countries). Across all centers, the best predictors ( $P < .001$ ) of outcome were type of onset (insidious vs acute) and type of setting (developed vs developing country), followed by marital status ( $P < .01$ ) gender ( $P < .05$ ), social isolation ( $P < .05$ ), and drug abuse ( $P < .05$ ). Neither type of family household (extended vs nuclear) nor experienced avoidance by others (a putative marker of stigma) reached statistical significance as predictor of outcome.

The authors concluded:

Nevertheless, “a strong case can be made for a real pervasive influence of a powerful factor which can be referred to as “culture,” as the context in which gene-environment interactions shape the clinical picture of human disease” (Jablensky & Sartorius, 2008, p. 254).

From this, most have concluded that the community inclusiveness and support that is often evidenced in poorer communities (developing countries), may be facilitative of recovery for people with serious mental illness. Indeed, health authorities in several countries have adopted community/social inclusion as part of their mental health policy.

## **Community Inclusion Implies Full Participation**

Full community or social inclusion implies engagement of people with and without serious mental illness in all aspects of community living, i.e., the full array of life domains: socialization, including friendships and intimate relationships, leisure activities, employment, education, housing, religious and spiritual activities, access to medical services and freedom to make decisions about those services and about providers, protection of legal rights, freedom from discrimination, solicitation of and respect for one’s opinion including expression of those opinions at voting polls, the right to free speech and to make decisions for oneself – all of those participation components that most of us take for granted (Salzer, Menkir, Shair, Drain & McClaine, 2006). Yet people with serious mental illness rarely have free access to these everyday aspects of community life. In most cases, those with serious mental illness are stigmatized and deemed not fit to participate.

According to Elliott and colleagues:

This occurs because of a perception that they lack the skills or abilities to carry out such an interaction, and is also influenced by judgments about the dangerousness and unpredictability of the person. Once the person is considered illegitimate then they are

beyond the rules of normal social behaviour and may be ignored or excluded by the group (Elliott, Ziegler, Altman & Scott, 1982).

The resulting social exclusion occurs at home, at work, in personal life, in social activities, in healthcare and in the media (Link, Struening, Neese, Asmussen & Phelan, 2002; Wahl, 1995) and leads to self-stigmatization as the individual internalizes the experienced stigma. Those with serious mental illnesses are also typically patronized and have decisions made for them, or they are openly denied access to opportunities, or they are so heavily questioned and ostracized that they simply choose to avoid taking advantage of the everyday rights and responsibilities that most citizens take for granted.

Most countries recognize the right of all individuals, including those with disabilities, to full community integration (UN Convention on the Rights of Persons with Disabilities, 2006). The United States affirmed this right with passage of the Americans with Disabilities Act (1990), which was updated in 2008 (Americans with Disabilities Act Amendments, 2008). The U.S. Supreme Court upheld the provisions of the Act by finding that unnecessary institutionalization of persons who, with proper supports, could live in the community, is a violation of the Act (Olmstead vs. L.C., 1999). The right to full inclusion is one which people with serious mental illness have yet to fully realize but is one that is at the heart of the recovery philosophy. Without full inclusion and acceptance, recovery from serious mental illness is considerably more challenging, if not almost impossible.

Social inclusion can be viewed as the degree to which individuals feel connected with their communities and others within and outside their communities and can be seen in contrast to social exclusion. When individuals are excluded they are marginalized and individuals from marginalized groups are often excluded. Individuals generally agreed to be most at risk of social exclusion include:

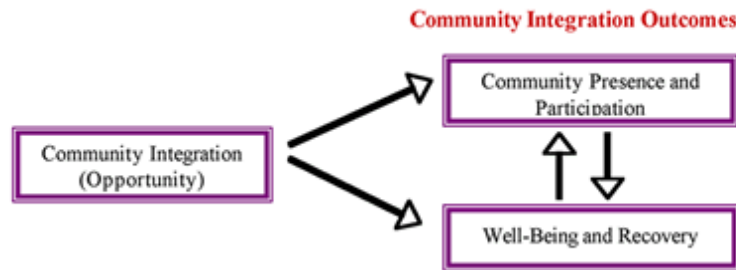
- Members of racial and ethnic minority groups
- People who are unemployed
- Those from “undesirable” groups such as prostitutes, users of illegal drugs, or those who espouse non-traditional values
- Immigrants and refugees
- People with physical and mental health impairments
- Those who are homeless

Community inclusion implies an additional concept, that of citizenship, with the attendant rights and responsibilities that go with that status. Both community inclusion and citizenship are tied to recovery and persons in recovery have responsibilities that are tied to citizenship. These include being a good neighbor, becoming involved in community activities, exercising the right to vote, fulfilling other citizenship duties such as obeying the law and helping others, etc. However, ensuring that all people, including those with

serious mental illnesses, are included as valuable members of their community is the responsibility of all and should not be seen as the responsibility of the person with the illness. The extent to which one is seen as a full citizen can be an indicator of the extent to which one is afforded, and exercises, rights to participation and making respected contributions to society (Rowe, Kloos, Chimnan, Davidson & Cross, 2001).

## Social Exclusion and Mental Health

Exclusion can lead to limitations on an individual’s ability to participate in the economic, social, legal, and civic opportunities available in the community. Being included and given the opportunity for community participation is recognized as an important ingredient for recovery from serious mental illness (Bromley, Gabrielian, Brekke, Pahwa, Daly, et al., 2013) and was depicted by Salzer in the following diagram:



Source: Salzer, 2006

And from a person with lived experience of serious mental illness:

*“For some of us, an episode of mental distress will disrupt our lives so that we are pushed out of the society in which we were fully participating. For others, the early onset of distress will mean social exclusion throughout our adult lives, with no prospect of training for a job or hope of a future in meaningful employment. Loneliness and loss of self-worth lead us to believe we are useless, and so we live with this sense of hopelessness, or far too often choose to end our lives. Repeatedly when we become ill we lose our homes, we lose our jobs and we lose our sense of identity. Not only do we cost the government money directly in health, housing and welfare payments, we lose the ability to contribute our skills and economically through taxes.*

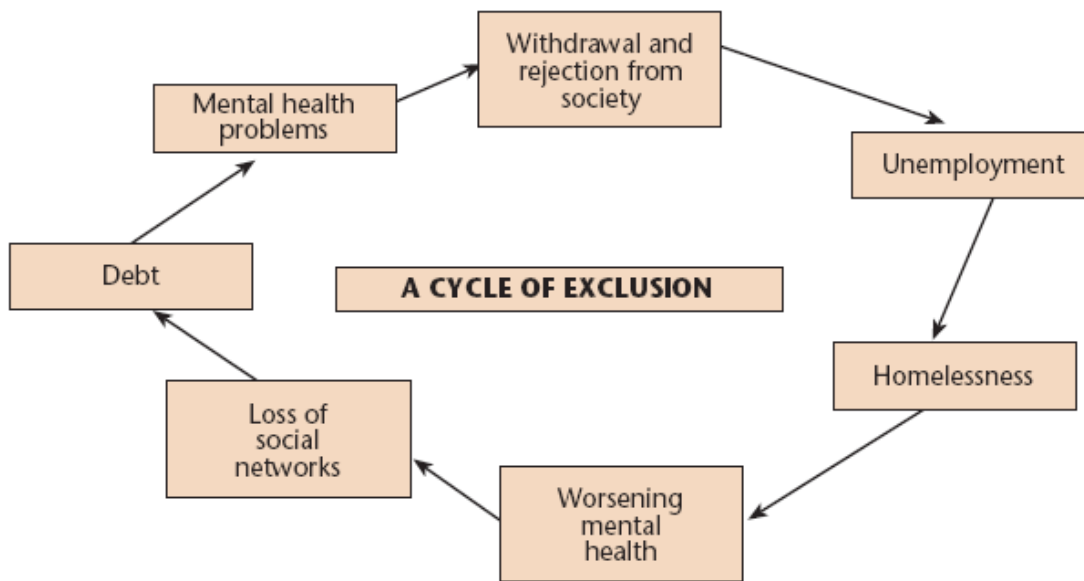
*“So we are perceived as a social burden. We lose sight of our potential, and when we try to move on, discrimination and stigma prevent us getting jobs that use our skills and experience and push us out of housing and education. The jobs we do get are poorly paid, and don’t utilise our skills and experience. And there are practical considerations – we stand to lose our financial security, whether state benefits or private insurance, when we attempt to rebuild our lives. We also stand to lose the health and social services that we find helpful, so that at the time when we most need support, our coping mechanisms are undermined. Moving back into society becomes a risky business.”*

Source: Office of the Deputy Prime Minister, 2004

This summary of the effects that serious mental illness can have on a person’s life is telling and shows that mental health problems can be both a cause and a consequence of social exclusion. It identifies the circular impact of illness, loss of opportunity, exclusion, and

increased emotional stress leading back to where the cycle begins again. The downward cycle of illness, marginalization, and exclusion is very difficult to escape. Even a short episode of mental health problems can have a long-term impact on a person's life, relationships and employment opportunities. A single hospital admission or period of sickness, or absence from work can lead to unemployment, homelessness, debt and social isolation. This can in turn lead to worsening mental health and the cycle of exclusion. And, mental health problems affect the whole family, not just one individual.

### Cycle of Exclusion



Source: Office of the Deputy Prime Minister, 2004

For example, a person who is slightly marginalized may be socially isolated and excluded (either intentionally or because he or she has not been involved before and is inadvertently left out), and the exclusion leads to loss of opportunities (for employment, housing, fulfillment of civic duties, etc.) and further marginalization and isolation. A person in such a circular circumstance can find it difficult to become involved, leading to further exclusion and isolation. Anyone who has ever been left out knows that this kind of situation can be hurtful and it is easy to see how it could be traumatic for a person trying to recover from serious mental illness.

### The Importance of Social Capital

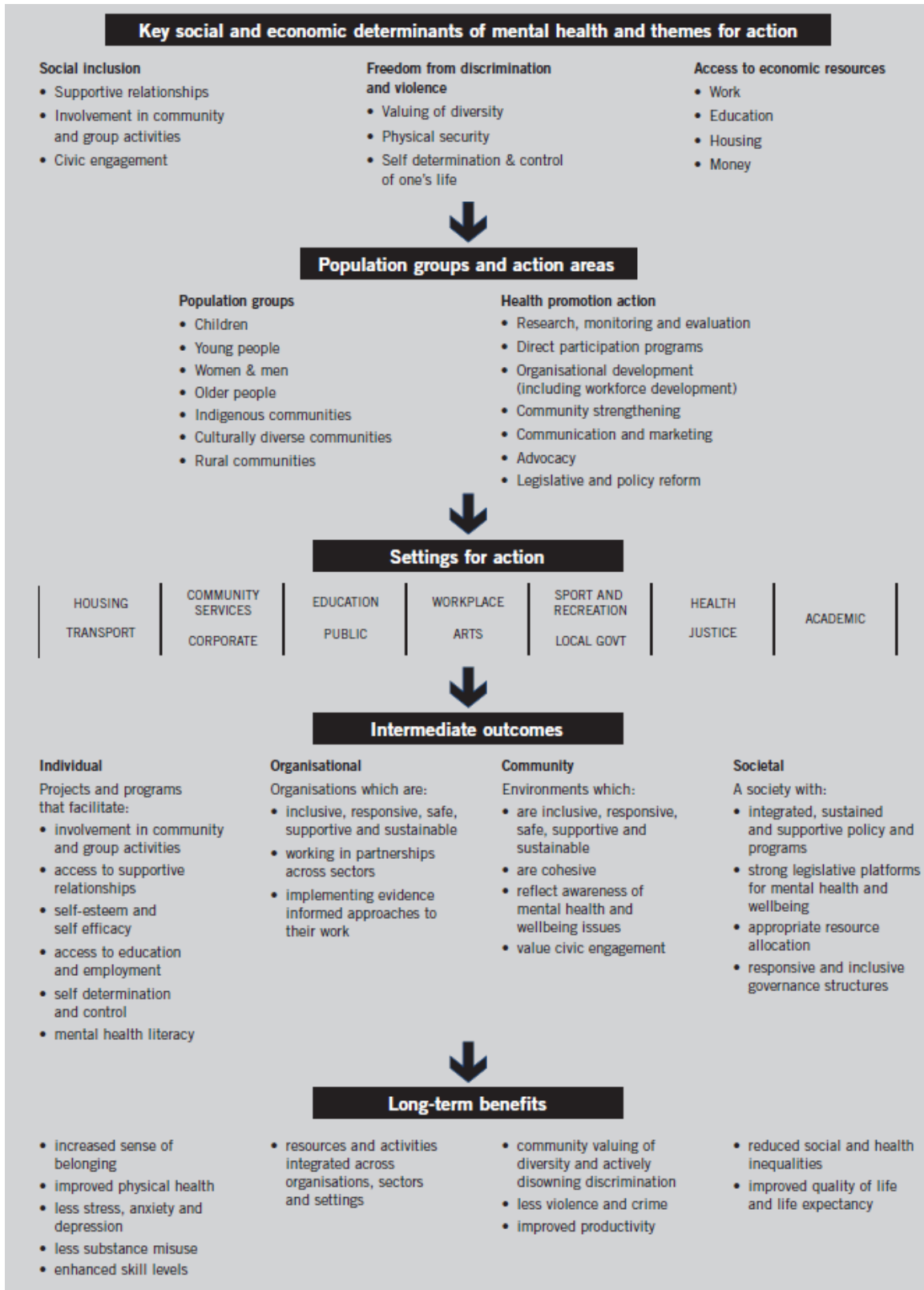
Development of social capital, i.e., the connections and sense of valuation between an individual and other members of society, is at the crux of community inclusion. Simply living in the community does not mean that one is included; rather, having social capital, being valued and connected to other members of the community fosters inclusion. In fact, a recent journal issue devoted to housing and social inclusion concluded that simply

providing housing, while undeniably important for well-being, did not increase perceptions of inclusion or participation among people with serious mental illnesses (Rosenheck, 2012).

The social networks (capital) that one has can be the determining factor in locating acceptable housing, becoming employed, and ultimately escaping from the cycle of marginalization, poverty, and exclusion. Several studies have highlighted the importance of social networks in finding suitable employment. For example, it is estimated that between 40% and 70% of people find their jobs through contact persons in their social networks (Fernandez & Weinberg, 1997; Granovetter, 1995; Putnam & Feldstein, 2003), and that good social networks play a part in increased wages and occupational prestige (Lin, 2001), although the impact on real wages has recently been disputed (Franzen & Hangartner, 2006). There is no question that a wider social network and contacts outside one's own immediate family and friends allow greater access to sources of information and opportunities.

Developing inclusiveness for all requires action at many levels ranging from individual and family levels to school levels and on to the wider community, and has wide ranging benefits for the larger society. The levels and benefits are depicted in the table below:

# Framework for the Promotion of Mental Health and Wellbeing



Source: Keleher & Armstrong, 2005



People with serious mental illnesses can recover from the effects of the illness, isolation and the exclusion that typically ensue, but need help and support from others. Examples of what is needed include:

- Inclusive communities: a willingness to accept “outsiders” by helping to reduce stigma and discrimination within the local community. The aim is to support reintegration and acceptance of people with mental health problems as equal citizens and community partners whose contributions are valued.
- Early intervention: offering support and help in a way that is non-stigmatizing and easily accessible before people reach a crisis point.
- Empowerment and the right to individual choice: breaking the perceived link between mental health problems and incompetence to provide individuals with control over their own care and future.
- A focus on employment: recognition that jobs provide a sense of worth and identity as well as financial security. People with serious mental illness often report that becoming employed is one of the most important goals they have. Despite this, extremely high levels of unemployment (80% to 85%) have been reported for people with serious mental illnesses (U.S. Census Bureau, 2007). In addition to the desirability of employment, working is associated with better health outcomes and reduced need for health and other services.
- Promoting broader social participation: education, training or volunteering, particularly in mainstream settings, can increase employment prospects as well as being valuable in their own right. These opportunities can help build self-confidence and social networks (capital), as can sports and arts activities. Like working, sports can help improve people’s physical as well as mental health.
- Securing basic entitlements: decent housing, basic financial and transport services, and ensuring people are aware of their rights to these and other basic services.
- Acknowledging people’s social networks and family relationships: recognizing the central role that family members and friends can play in reintegration into communities.
- Building confidence and trust: making services more welcoming and promoting understanding of different needs to encourage people who may mistrust statutory services, such as people from some ethnic communities, to engage with services earlier (Office of the Deputy Prime Minister, 2004).

A framework for mental health policy that highlights community inclusion can be seen from the following which outlines three social and economic tenets:

1. Social inclusion, including:

- Social and community connections

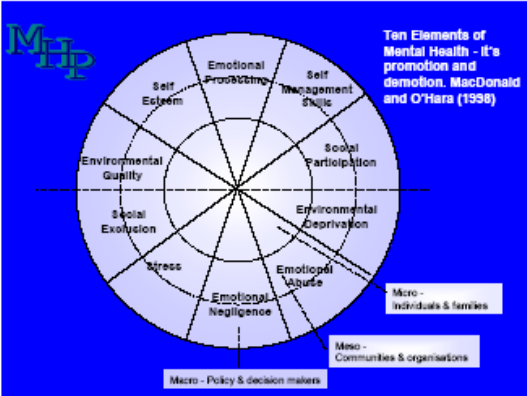
- Stable and supportive environments
  - A variety of social and physical activities
  - Access to networks and supportive relationships
  - A valued social position
2. Freedom from violence and discrimination, including:
- The valuing of diversity
  - Physical security
  - Opportunity for self-determination and control of one's life
3. Access to economic resources and participation, including:
- Access to work and meaningful engagement
  - Access to education
  - Access to adequate housing
  - Access to money (Keleher & Armstrong, 2005).

## **An Ecological Perspective**

The idea that individual behavior occurs within the context of a variety of other factors which could be labeled "culture" is widely acknowledged and was espoused succinctly by the Task Force of the Association of Applied Behavior Analysis which concluded that "behaviors occur within a context and often are a function of the person's physical, interpersonal and programmatic environment" (Van Houten, Axelrod, Bailey, Favell, Foxx, et al., 1988). Most assume that acceptance of individual differences and provision of social support can lead to a more normalized experience as individuals are considered part of the community with full participatory expectations and rights.

This view of social inclusion and the effect that factors external to the person can have on behavior is often referred to as an ecological framework or perspective. An ecological perspective takes into account both individual characteristics and the surrounding environment. The interaction between individual variables and those of his or her environment is frequently complex. Individuals live and interact within an interpersonal and environmental context and behavior is generally a function of the interplay between a person's physical and interpersonal environment. This is depicted below:

## Elements of Mental Health – Positive and Negative Influences

<b>Promoting Elements</b>		<b>Demoting Elements</b>
<p><b>Ensuring Environmental Quality</b> Which encompasses a range of environmental influences, creating sustainable conditions and structures for the development of, for example, a clean environment, positive housing and transport systems, attractive buildings and landscaping, such as parks, play areas and increased accessible leisure facilities, all of which can have a positive effect upon our mental health.</p>	<p><b>Ten Elements of Mental Health Its Promotion and Demotion</b> The ten-element map describes different elements of mental health, five, which promote mental health (above the dotted line) and need to be increased and five which demote mental health (below the dotted line) and need to be reduced</p>	<p><b>Reducing Environmental Deprivation</b> Including for example, reducing poor housing, lack of safe play areas, lack of transport, threats of violence, poverty and debt. Toxic pollutants, alcohol and other drug use</p>
<p><b>Raising Self Esteem</b> By self-esteem we mean the belief about our self worth, which we learn through our social interactions. Sometimes said to be "the reputation you have with yourself". It is about encouraging the development of a positive self-image. Creating opportunities for personal achievement, development of a sense of self worth and feeling valued through, for example, school and employment</p>		<p><b>Eradicating Emotional Abuse</b> Emotional abuse can be described as the systematic denial and destruction of self esteem and involved the abuse of our powers as either parents, peers, teachers, partners, carers or employers, by limiting, deforming or in other ways harming full emotional growth. It shouldn't be tolerated but unlike other forms of abuse it often is.</p>
<p><b>Encouraging Emotional Processing</b> By this we mean promoting an awareness and respect for our own emotions and those of others. Developing a wide emotional vocabulary as well as having the esteem and skills to express our emotions and hear them in others. It is about giving people the opportunity from an early age to learn how to, or be able to feel comfortable, expressing emotions in a creative and productive way throughout their life. Where the expression of a range of emotions is encouraged and socially accepted in different situations, for example, in the home, in school and in the workplace.</p>		<p><b>Diminishing Emotional Negligence</b> Emotional negligence refers to institutional or personal neglect in helping people to develop and express their emotional life. It can be seen through inadvertent criticism, the denial of our uniqueness and significance, the devaluation of our values or the belittling of our competencies and our success. It can be seen in the over medicalised, de-humanised treatment regimes for physical and mental health problems.</p>
<p><b>Developing Self Management Skills</b> Such skills are not just coping; they are more varied, holistic, more proactive and involve an internal locus of control (a sense that we can influence what happens to us in our lives). It includes activities that create opportunities, so that from an early age and throughout life, people can learn and develop the skills to manage in difficult situations or circumstances and manage change positively. Importantly it involves activities that ensure access to resources, for people and communities to enable a sense of being in control of their lives.</p>		<p><b>Alleviating Stress</b> Stress can come from many sources - including environmental factors such as poor housing, deprived localities etc. A key to promoting mental health by reducing stress, is to work with people to help to identify stress in their own terms. We should avoid an over emphasis on individual stress management as we also need to tackle the sources of stress. In addition there can be an over emphasis on coping as there will be times when not coping is understandable and healthy.</p>
<p><b>Encouraging Social Participation</b> This is about creating the opportunities for active involvement and active participation for people, coming together for the positive development of their communities: creating the conditions where positive relationships are based on the acceptance of difference and diversity; creating a sense of citizenship, that is the entitlement of social rights as well as the acceptance of social responsibilities; creating structures to support increased social systems and networks, for example with families, communities, in the workplace and school.</p>		<p><b>Reducing Social Exclusion</b> Being excluded because of gender, race, class, is about exploitation and requires tackling, whether or not there is an observable example of the negative mental health effects of social exclusion. Intervention needs to be at a number of levels, most often it is the societal, organisational / community or environmental issues that need addressing.</p>

**Relationship between the Levels**

Integrated action must occur across the levels between individuals, families, communities, organizations, and policy makers. So for example, work on self-management skills within a schools personal and social education program is clearly going to be jeopardized if bullying behavior of staff or children across the school (organizational level) is undermining good work in the classroom (individual level). In addition, the work is likely to be more effective if it addresses other interpersonal issues in the life of the school and its community (organizational and community level). For example, how teachers, parents and children communicate with each other, approaches to reward and punishment, etc. instead of just concentrating on work with individuals. Interconnected problems require interconnected solutions.

Source: McDonald & O'Hara, 1998

Several of the factors depicted above are central to the promotion of social inclusion and mental health. Some focus on increasing positive components and others focus on decreasing less desirable components. By encouraging people to feel good about themselves, helping them to develop skills that will help them achieve their goals, assisting with attainment of good housing, social activities, and employment opportunities, while at the same time refusing to accept or sanction (even by silence or inaction) discrimination, stigmatization, marginalization, or policies and practices that are, or have the potential to lead to exclusion, and by working to change environments that are dehumanizing and emotionally toxic, psychologists can actively promote social inclusion and an environment conducive to recovery from serious mental illness. When communities do not focus on increasing positive components and decreasing negative ones, individuals with serious mental illnesses often exclude themselves for fear of further stigmatization, rejection, behavioral flare-ups, and instead seek out situations where others with similar conditions are present and where they will be more readily accepted (Bromley, Gabrielian, Brekke, Pahwa, Daly, et al., 2013).

## **Mental Health Professionals in the Mental Health Service Delivery System**

To ensure that all people are afforded the opportunity for full and respectful participation, health and social policies must encourage that individuals from potentially marginalized groups are sought out and informed of opportunities to be involved and participate. Unfortunately, despite the good intentions of most mental health services, there are typically few if any, attempts to build social networks outside of the mental health service (Condeluci, 2008). Some would even argue that peer support networks, despite the unquestionably important role they play in connecting people to others in recovery and providing strong emotional support, may foster closed networks that keep individuals from developing wider social ties.

Psychologists and other mental health providers have a responsibility to work to ensure full integration as part of the treatment and rehabilitation services provided rather than assuming that these will be taken care of by someone else after the person leaves the service system (Farkas & Anthony, 2010; Tondora, 2011). Research has shown that education and contact with people with serious mental illnesses are critical to reducing stigma, discrimination, and to increasing acceptance and inclusion. A recent meta-analysis of research has identified that while both education and contact are important, there may be differential benefits depending on the age of the individuals involved. These authors found that

...contact was better than education at reducing stigma for adults. For adolescents, the opposite pattern was found: education was more effective. Overall, face-to-face contact was more effective than contact by video (Corrigan, Morris, Michaels, Rafacz & Rüsçh, 2012).

Ideally, psychologists would take an active role in promoting full inclusion of people with serious mental illness. The American Psychological Association's Ethical Principles of Psychologists and Code of Conduct (2002) encourages psychologists to advocate for the rights of all individuals, especially those who are most vulnerable:

Psychologists respect and protect civil and human rights and the central importance of freedom of inquiry and expression in research, teaching, and publication. They strive to help the public in developing informed judgments and choices concerning human behavior (Preamble, p. 3).

Psychologists respect the dignity and worth of all people, and the rights of individuals to privacy, confidentiality, and self-determination. Psychologists are aware that special safeguards may be necessary to protect the rights and welfare of persons or communities whose vulnerabilities impair autonomous decision making (Principle E: Respect for People's Rights and Dignity, p. 4).

What can psychologists do to help facilitate community inclusion? Psychologists and other practitioners can ask themselves what their true beliefs are about including people with serious mental illnesses in full community participation and look inward to see if their behaviors reflect an openness to inclusion. At the same time, psychologists have an ethical duty to actively advocate for real inclusion of all individuals, in workplaces, community centers, religious institutions, and in social circles.

Community level interventions such as those in the examples below may be needed to help people with serious mental illness become and remain connected to their communities, avoid isolation, and ultimately achieve recovery. Unfortunately, mental health service delivery systems rarely take responsibility for ensuring that these are in place, resulting in a substantial void and differential between what we know should be done and what is actually available. Given the ethical mandate that psychologists have to advocate for the rights of individuals who are most vulnerable, psychologists should feel compelled to take on the responsibility for ensuring that needed supports and services are available. Some examples of these services and supports include:

- Social support programs designed to reach out to isolated individuals
- Opportunities for volunteering
- Workplace mental health promotion
- Structured community opportunities for participation
- Media campaigns for mental health promotion

## **Assessment and Interventions from an Ecological Perspective**

Because of the influence of external factors, the totality of the person's experience should be accounted for when conducting assessments, helping with goal definition, and developing intervention strategies. People with serious mental illness have reported that they have

sometimes felt traumatized by assessments. Not only are psychologists required to be sensitive to the needs and circumstances facing every individual, consideration of the external variables that may have a significant impact on one's behavior is essential. Without such consideration, a high proportion of the variance that could account for the person's behavior will likely be unaccounted for. Likewise, helping a person identify strengths and deficits and set goals and without taking into account the people and other resources available, does a considerable dis-service to the person who will likely have assets or needs that are crucial to attainment of the goal. A person centered and strengths based assessment framework will go a long way to helping individuals feel valued, be more involved in their mental health team, become true partners in their recovery process, and, thereby become less isolated.

Interventions designed to teach people skills needed to achieve their goals can be aimed at assisting individuals to feel confident about participating in community activities. Interventions can be dependent on available resources, either those that the community has to offer or those that individual family, friends, or helping professionals have to offer, but must always be geared to helping the individual reach his or her goals.

Promoting community inclusion involves interventions designed to build social capital, promote community wellbeing, overcome social isolation, increase social connectedness and address social exclusion. Psychologists can assist individuals by using behavioral shaping methods to teach skills for accessing and using community facilities, teaching social and communication skills to ensure individuals feel confident about their abilities to participate and helping people to become connected to support and peer groups. CBT and other psychological treatments to improve cognition, self-esteem and confidence can be of great help to those struggling to deal with the devastating effects of internalized and external stigmatization (Thorncroft, Brohan, Kassam & Lewis-Holmes, 2008).

All of these components, i.e., inclusion versus exclusion, encouragement of community policies that welcome and encourage participation, incorporation of an ecological view into assessments and intervention development, person centered care, and advocacy for social inclusion policies, are important components of the mental health practitioner's toolbox that should be used by psychologists to help people with serious mental illnesses achieve the goals they set for themselves.

## **Challenges**

The U.S. has a long history of excluding those who seem a bit different: people with disabilities and impairments of all kinds, people from non-majority cultures, people from non-majority religions, people who are poor – the list could go on and on. Changing the perception of decision makers and other influential members of society so that people with serious mental illnesses are seen as valued members of the community, especially when many individuals with such illnesses exhibit odd behaviors, can be difficult. It is only when

education is provided and contact is made between individuals with, and without, these illnesses, that the added value of incorporating everyone can be appreciated.

Mental health services themselves and the people who work in them also have biases and exhibit exclusionary practices. A simple example is that in many mental health systems, there are separate restroom facilities for staff versus clients of the service. This would seemingly be an easy place to start to break down barriers and demonstrate inclusiveness. Yet, even mental health professionals often resist such changes. Changing the values and practices of communities will continue to be difficult as long as psychologists and other mental health providers retain their own biases and stigmatizing behaviors.

## Summary

Including people as part of their community is important whether or not they have a serious illness. This can be critical for people with serious mental illness because they are more prone to social isolation due to stigma, fear of rejection, possible alienation from family, and financial issues that place limitations on their participation.

Social inclusion implies full acceptance of and participation by, all those in the community, in all aspects of society from leisure activities through to civic rights such as decent housing, voting rights, and equal protections under the law. However, people with serious mental illness cannot recover in isolation from the larger community. In order to accomplish movement out of the treatment system and into the mainstream of society, regular activities and opportunities must be available and encouraged for everyone. Unless true access is afforded with encouragement and support for participation, individuals with serious mental illness will continue to feel excluded and will not attempt to make the leap into mainstream society.

Results of international research have consistently indicated that there may be benefits that derive from cultures where people with serious mental illnesses are integrated into their communities although other factors such as medication availability, acute versus insidious onset, etc. most likely contribute to this effect as well. Although the relationship is not totally clear, most agree that excluding people with serious mental illness is neither beneficial nor conducive to their recovery.

When taken together, the multiple factors in which people live and interact influence behavior, which in turn can influence future interactions. These complex interactions must be taken into account when assessments and interventions are developed.

Psychologists should ensure that their own biases do not contribute to stigmatization and isolation of people who are different, who are ill, who are poor, etc. Psychologists and other mental health professionals must become actively involved in advocating for full inclusion of all members of society, especially those who are most vulnerable in order to ensure full participation and facilitate the process of recovery.

## Sample Learning Activity

This activity involves discussion about the implications of inclusion versus exclusion based on marginalization that usually accompanies serious mental illness and should ideally be completed with one or more consumers as participants.

1. Discuss how easy it might be to become marginalized based on economic disparity, race, gender, sexual preference, health or disability status including mental health status, etc.
2. What actions are required to promote inclusion and full participation of people with serious mental illnesses in society?
3. What are the pros and cons of encouraging people with serious mental illness to become actively involved in the election of local and national officials?
4. What are the ethical responsibilities of psychologists in promoting social policies that favor full social inclusion?



## Sample Evaluation Questions

<u>Question</u>	<u>True</u>	<u>False</u>
1. People with serious mental illness do not want to be offered opportunities to participate in their community because these opportunities are too frightening and demanding		X
2. Building a life in the community is a task that begins in advanced stages of recovery when someone is preparing for discharge		X
3. Although people with serious mental illness should have full civil rights, they should be discouraged from voting or making important life decisions because of their cognitive impairments		X
4. The quality of one's environment is not relevant to serious mental illness because these are brain disorders that will influence a person for the rest of his or her life		X
5. The behavior of people with serious mental illness should be attributed only to factors within the person so that interventions can be developed that assist the person to control these internal variables		X

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## **Additional Resources**

American Psychological Association Recovery to Practice Initiative.

<http://www.apa.org/pi/rtp>

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## Citing the Curriculum

Citation for this Module:

American Psychological Association & Jansen, M. A. (2014). Community Inclusion. *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

Citation for the full Curriculum:

American Psychological Association & Jansen, M. A. (2014). *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

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# American Psychological Association

## Recovery to Practice Initiative Curriculum: Reframing Psychology for the Emerging Health Care Environment

### *13. Peer Delivered Services*

August 2014

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## Overview

This module presents a discussion and review of services delivered by consumers who have recovered sufficiently to use their experiences to be of help to others with similar illnesses. There are several different kinds of peer delivered services and these are presented in this module. There are many terms used to refer to services provided by peers and this module attempts to clarify these to the extent possible. Most often individuals who offer services to consumers are referred to as peer providers and that connotation is used in this module except where the person is engaged in the particular service model known as peer support. In this case, the provider is referred to as a peer support worker or as peer support personnel. There are other titles used such as peer specialist, but this can connote a Certified Peer Specialist who has received a certain kind of training and is certified. Not all peer support personnel are certified; thus peer support worker or personnel are used.

Peer delivered services are relatively new in the mental health service delivery arena, although these services have proliferated across the U.S. Consequently, research on the various models is fairly recent and some reviews of the individual studies have been completed recently. Findings from these reviews along with the issues and challenges of implementing peer delivered services are presented.

## Learning Objectives

At the end of this module you will be able to:

- Describe at least two of the different models of peer delivered services
- Identify three characteristics of peer support
- State three key research findings related to peer support and peer delivered services; include findings for individuals receiving services from peers, findings related to peer providers, and finding related to service systems
- Describe two issues that must be addressed to implement peer delivered services

## Resources

- Lecture Notes
- Required Readings
- Lecture Notes Citations
- Sample Learning Activity
- Sample Evaluation Questions
- Additional Resources

## Required Readings

Davidson, L., Bellamy, C., Guy, K. & Miller, R. (2012). Peer support among persons with severe mental illnesses: A review of evidence and experience. *World Psychiatry*, 11, 2, 123-128.

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Solomon, P. (2004). Peer support/peer provided services: Underlying processes, benefits, and critical ingredients. *Psychiatric Rehabilitation Journal*, 27, 4, 392–401.

## Activities

Complete the following activities:

- Read the lecture notes
- Read the required readings
- Engage in a learning activity related to this module
- Evaluate students' understanding of this module.

## Lecture Notes

People with lived experience of serious mental illness are strongly encouraged to be part of the delivery of the curriculum including being active participants in the delivery of the lecture. Refer to the curriculum Instruction module for additional information.

### Introduction

Participation of consumers in the design, delivery, and evaluation of mental health services is one of the hallmarks of a mental health system that truly supports the principles of recovery. In the U.S., programs and services offered to consumers by their peers have surpassed the number of professionally operated programs (Goldstrom, Campbell, Rogers, Lambert, et al., 2006).

Peer providers may be current or former users of the mental health system, who have achieved a level of recovery that allows them to be helpful to others going through the recovery process. People with lived experience of mental illness consistently report that having the support of others who have experienced what they are going through is one of the most important and helpful services. Several studies have confirmed these perceptions of their experiences (Dumont & Jones, 2002; Nelson, Ochocka, Janzen & Trainor, 2006; Piat, Sabetti, Couture, Sylvestre, et al., 2009).

### Models of Peer Delivered Services

There are many different types of services that peers offer and there is overlap among the types of services both in the literature and in practice (Chinman, George, Dougherty, Daniels, Ghose & Swift, 2014). While they all involve some level of help or support from a peer, the various services have been differentiated by characteristics such as where they are delivered, how the service is managed, whether or not the service is part of a traditional mental health system, and the role that the person is performing.

This is an emerging area of service delivery and the extant literature often discusses different models in similar ways. Many categorizations of the various services could be offered - one delineation of peer delivered services is as follows:

- Peer led self help interventions that can involve sharing experiences, offering information, e.g., in a mutual support education group, or teaching others how to develop a recovery plan such as a Wellness Recovery Action Plan (WRAP) (Copeland, 2002)
- Telephone services such as a “warm” line
- Peer operated and managed services
- Traditional mental health services such as case management delivered by peer providers within the mental health system

- Peer support programs, offered as an individual or group service most usually within a traditional mental health service, although the service can be provided by an agency outside the mental health system.

The following information clarifies the different models to the greatest extent possible.

### **Peer Led Self-help Interventions**

Peer led self help interventions can include a variety of formats; two that have been discussed in the literature include 1) groups to help others learn about their illness and develop wellness activities and strategies and 2) mutual support education groups.

#### *Peer Led Recovery Education Groups*

Anyone who has ever experienced a serious illness recognizes the value of learning about the illness and developing tools to stay healthy and cope with symptoms that may recur. Peer led recovery education groups can be very useful for helping people learn about wellness activities, the importance of good nutrition, stress management techniques, and community resources that are available. Wellness management and recovery groups (sometimes referred to as illness management and recovery) and educational activities such as Pathways to Recovery (Ridgeway, McDiarmid, Davidson, Bayes & Ratzlaff, 2002) are examples.

Another example that has become widely utilized is a recovery action planning tool that is considered highly useful because it can facilitate action by the person to identify and notice triggers or symptoms that are becoming more pronounced. It can also facilitate action by the person's support network when they notice that the person is in need of assistance. A clinician's treatment planning efforts ought to be directly informed, and can be facilitated by, such personally developed recovery plans. A recovery action plan can include items such as reminders about triggers, activities to stay healthy, a crisis plan, and instructions given by the person about actions to be taken by supporters when certain conditions are met. The most well known recovery action plan is WRAP (Copeland, 2002), and research has shown that people who have developed a WRAP have reported significantly increased awareness of early warning signs, awareness of symptom triggers, increased use of wellness tools, increased likelihood of having a crisis plan in place, and increases in having a social support system (Cook, Copeland, Corey, Buffington, et al., 2010).

#### *Mutual Support Groups*

As with other support groups, i.e., disorder specific support groups (cancer, cystic fibrosis, multiple sclerosis, etc.), or mutual support education groups can be a venue for giving and receiving support, gaining new knowledge about a wide array of topics from housing to new services, to tools to remain well, etc. Just as with other support groups, a support group for people with mental health disorders can be face to face or can be internet based. Studies have found that participants report positive outcomes including improved functioning and illness management, increased self esteem and self efficacy, increased

feelings of optimism and social support, and reduction in self reported symptomatology (Christensen & Jacobson, 1994; Fukui, Davidson & Rapp, 2010; Powell, 2001; van Gestel-Timmermans, Brouwers & van Nieuwenhuizen, 2010).

### **Telephone Services Such as a Warm Line**

A relatively new service that is available in some locations for people in recovery is called a warm line. A warm line can be used when someone is in crisis, but is more often thought of as a service that people can call to obtain support, alleviate loneliness, and obtain help with symptom management. Often warm lines operate after traditional services have closed, i.e., after normal business hours, and are staffed by trained peer providers who have access to an on-call supervisor for those calls that present an emergency or crisis situation. Although research is limited, one study has found that users reported substantially reduced need for crisis services, increased sense of well-being (defined as increased ability to function well) and increased sense of personal empowerment (Dalgin, Maline & Driscoll, 2011).

### **Peer Managed and Operated Services**

Services that are wholly managed and administered by people with lived experience of serious mental illness are another category of peer delivered services. These services are not affiliated with a traditional mental health service and may have people who have not experienced a serious mental illness within the organization. The key point is that decisions are made by peer providers who “own” and operate the service rather than by non-peers who may happen to work in the program (Substance Abuse and Mental Health Services Administration, 1998; Solomon & Draine, 2001). Often these programs are freestanding entities and have both paid staff and volunteer staff. These services can take any form and common examples include drop-in centers, clubhouses, crisis services, educational and employment services, and peer support programs (Solomon, 2004).

### **Traditional Mental Health Services Such as Case Management Delivered by Peer Providers**

Increasingly, people with lived experience of serious mental illnesses are working within traditional mental health systems, serving in a variety of staff roles. A common example is case management, but individuals with lived experience are also working in a wide range of other professional positions. In some cases, these individuals have disclosed their mental health history; in other cases, they have not and choose to keep their health information private.

While those individuals who have disclosed their history may be able to provide support to their clients, they are generally not considered to be providing peer services if they are providing traditional mental health services because their primary function is to fulfill their staff role, i.e., as a case manager, social worker, psychologist, psychiatrist, administrator, etc., rather than to provide peer services.

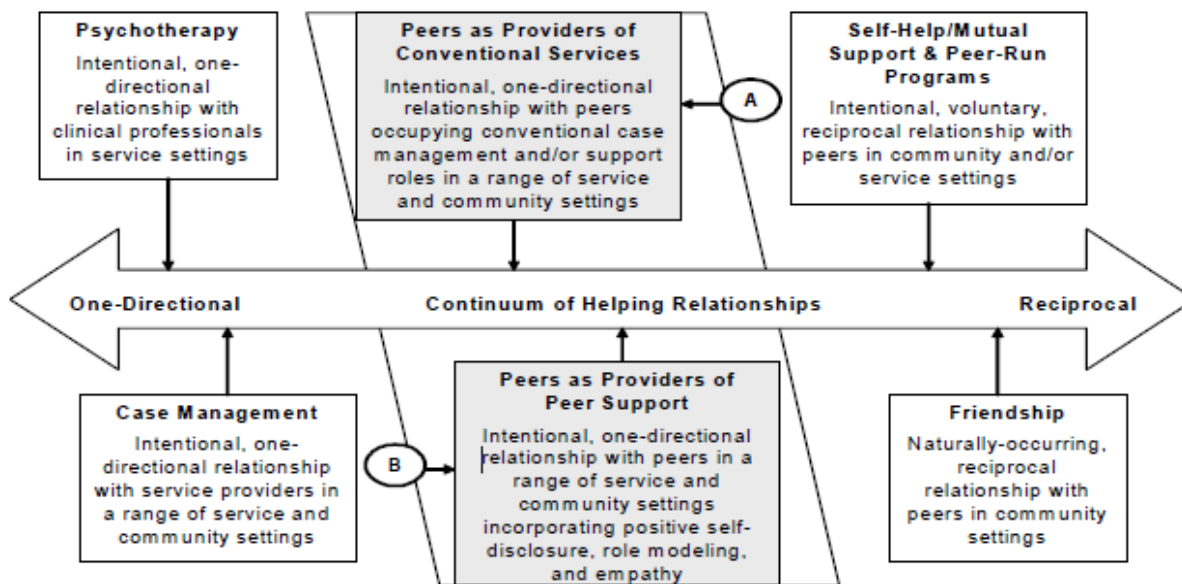
## Peer Support Programs

Peer support programs within a traditional mental health service are increasingly recognized as an important component of the service; there are also independent peer support agencies that can be contracted to offer the service outside the formal mental health system. Because of the value attached to the service by consumers, peer support is increasingly available in many countries around the world.

As mentioned, there are many models of service delivery where peers provide services to others with similar mental health conditions, and there is overlap among the models (Chinman, George, Dougherty, Daniels, et al., 2014). One way of distinguishing between these has been proposed by Davidson and his colleagues (Davidson, 2010; Davidson, Chinman, Sells & Rowe, 2006), and involves the issue of reciprocity, or the benefits that accrue to the provider versus the recipient of services. In this conceptualization, the peer support worker is not the beneficiary of service provision, i.e., does not receive reciprocal benefit from helping his or her peer, at least not to the extent that one would benefit from a mutual support group for example. Davidson has characterized this as “involving an asymmetrical—if not one-directional—relationship, with at least 1 designated service/support provider and 1 designated service/support recipient” (Davidson, 2010).

The graphic below depicts this with the varying relationships that can operate within the service delivery system.

**A Continuum of Helping Relationships among Adults with Serious Mental Illness**



Source: Davidson, L. (2010).

Because of the prevalence of peer support services, principally operating within mental health service delivery systems and the interest in the benefits they have for other consumers, the focus of the remainder of this module is primarily on these services.

There are several definitions of peer support including the following:

...as involving 1 or more persons who have a history of mental illness and who have experienced significant improvements in their psychiatric condition offering services and/or supports to other people with serious mental illness who are considered to be not as far along in their own recovery process (Davidson, Chinman, Sells & Rowe, 2006).

...peer support, understood as a sharing of personal experiences and provision of mutual aid, encouragement of self-determination and personal responsibility (Salzer, Schwenk & Brusilovskiy, 2010).

The following elements are generally considered to be common to peer support services:

- A person with lived experience of severe mental illness works with one or more people with a similar illness and or similar experiences providing hope, support, encouragement, information, education, role modeling, and mentoring;
- The peer support worker is a current or former user of mental health services and is further along in his or her recovery, having overcome many of the barriers of living and working in the community to be able to be of assistance;
- The peer support worker discloses his or her status as a person with lived experience of serious mental illness and shares information about how he or she has learned to cope, make progress in recovery, and deal with various situations as they arise;
- The peer support worker offers “conditional regard”, i.e., acceptance of the person within an empathic framework while helping the person accept responsibility for taking charge of his or her health and life;
- The peer support worker is paid for his or work and is most commonly part of the mental health staff although peer support workers may at times provide services in an independent organization (Davidson, Bellamy, Guy & Miller, 2012; Davidson, Chinman, Sells & Rowe, 2006; Salzer, Schwenk & Brusilovskiy, 2010).

Unfortunately, peer support personnel are not always paid appropriately for the service provided and are sometimes relegated to performance of tasks that are not the purview of peer support workers (Gates, Mandiberg & Akabas, 2010). These issues are discussed further in later sections of this module.

### **What Peer Support Workers Do**

Peer support workers assist consumers who are striving to recover from the effects of their illness. Some of these effects are impairment or disability, deterioration in physical health, institutionalization, homelessness, unemployment, poverty and involvement in criminal justice systems. Peer support workers listen, share their own experiences, and offer support, hope, encouragement, education, and practical suggestions. Peer support workers can perform a variety of services from mentoring by offering advice and modeling

approaches to attaining goals, teaching skills and behaviors for managing illness and remaining well, taking personal responsibility and achieving success in the community, and providing practical assistance with housing, medication, entitlements, schooling, employment, etc. (Davidson, Chinman, Sells & Rowe, 2006; Salzer, Schwenk & Brusilovskiy, 2010).

Peer support programs, like other peer delivered services, are provided by individuals who have experienced a serious mental illness and who have recovered sufficiently that they can be helpful to their peers who have similar problems. Peer support workers can work individually or in groups, and can also provide help and supportive services in the community. Peer support workers are employed in a variety of program settings including case management, psychosocial programs, supported education and employment programs, clubhouses, recreation and leisure programs, to name but a few.

## **Benefits of Peer Support**

Since the introduction of peer support services in the early 1990s, there has been considerable interest in determining the benefits that consumers might receive from them. A brief summary of what has been learned to date follows.

### **Benefits for Recipients of Peer Support**

There have been several reviews of the published literature on peer support and while there is overlap in the models and services studied, there is presently a fair amount of consensus about the beneficial effects of peer support and peers as providers of other services such as self help and educational groups. While individual studies and reviews of those studies have not shown differences in traditional outcomes (employment, housing, etc.), benefits for people receiving peer support have been demonstrated. Additionally, there are benefits for consumers who serve as peer support personnel. As mentioned, there is frequently overlap between the models and services studied or reviewed but some conclusions can be drawn about the benefits of receiving services from a peer. A brief review of some of the more salient findings follows.

#### *Engagement and Retention in Treatment*

One of the most consistent findings from the reviews of studies done to date is that there are benefits for consumers who receive peer support services as they are likely to become more engaged and more involved in their treatment and their retention in treatment may be more likely; this seems especially true for people who might not normally be likely to engage in treatment (Repper & Carter, 2011; Rogers, Kash & Brucker, 2009). In some studies, effects tend to disappear after a period of time (six to twelve months) (Jewell, Davidson & Rowe, 2006; Sells, Davidson, Jewell, Falzer, et al., 2006). As stated by Davidson and colleagues:

In terms of possible active ingredients, these findings appear to support peer providers' abilities to forge effective and stable working alliances early in the



treatment process with clients typically viewed as among the most disengaged from traditional approaches to care. Consistent with earlier suggestions of Solomon and colleagues (1995), these findings also suggest that differences between relationships with peer specialists and those with regular case managers may tend to surface early in the engagement process and eventually dissolve over time, as non-peer providers “catch up” in forming stronger working alliances with their clients (Davidson, Chinman, Sells & Rowe, 2006).

Peer support workers may be better able to communicate acceptance, understanding, hope and positive regard which helps their clients to be more accepting of treatment and ultimately more motivated to use community services that are peer based (Davidson, Chinman, Sells & Rowe, 2006; Repper & Carter, 2011). For consumers who are alienated from the mental health treatment system, facilitating engagement and retention in services would seem to be important for recovery.

#### *Longer Community Tenure between Hospitalization and Fewer Days in Hospital*

Another often reported finding is that for individuals with frequent hospitalizations, effects such as reduced time to re-hospitalization and fewer days in hospital when hospitalization did occur have been found, although some of these studies involved using peers as case managers, rather than as peer support workers (Davidson, Bellamy, Guy & Miller, 2012; Repper & Carter, 2011; Simpson & House, 2002; Solomon, 2004). There have also been individual studies that have shown similar effects and a recent study that has found decreased levels of depression and increases in hope, self-care, and sense of well-being (Clarke, Herincks, Kinney, Paulson, et al., 2000; Sledge, Lawless, Sells, Wieland, et al., 2011).

#### *Symptom Stability, Self-Esteem, Empowerment, Coping Skills, Social Support*

Additionally, findings from reviews of individual studies indicate that for those who regularly engage in peer delivered interventions in a group context such as a mutual support group, benefits are seen in such areas as symptom stability, abstinence from substance abuse, self esteem, self efficacy, empowerment, quality of life, perceived social support, satisfaction with services, coping skills, medication adherence, reduced criminal justice involvement, greater social support and more friends, and greater integration into their community (Repper & Carter, 2011; Rogers, Kash & Brucker, 2009; Salzer & Mental Health Association of Southeastern Pennsylvania Best Practices Team, 2002; Solomon, 2004).

#### *Cultural Sensitivity and Hope, Illness Management and Satisfaction*

Finally, a recent area of investigation that had been ignored in the literature until recently is the potential benefit of providing peer support services in a culturally sensitive environment. One recent study that investigated the benefits of culturally responsive peer providers found that helping people pursue desired community activities and roles in addition to providing illness management and recovery in a person centered treatment modality led to an increase in hope and engagement in managing their illness, positive

feelings of self and life, satisfaction with family life, social support and sense of community belonging, and decreased psychotic symptomatology (Tondora, O'Connell, Dinzeo, Miller, et al., 2010).

### *Facilitation of Community Integration*

Although infrequently mentioned, a benefit of including peer workers in mental health services is that peers can also enhance social networks and facilitate the integration of individuals with serious mental illnesses into all aspects of their community. Salzer and colleagues highlighted several reasons for this, including the following:

- Peers believe in self-determination
- Peers understand environmental barriers (i.e., poverty, transportation, prejudice and discrimination)
- Peers do not have as many pre-conceived notions about what they should be doing and how they should be doing it as traditionally trained practitioners often do (Salzer, Baron, Menkir & Breen, 2013).

Clearly, helping individuals to be connected to friends, family, and their community is facilitative of recovery and using peers to help achieve this goal may be one of their most important potential contributions, not only for those receiving services but for the community as well.

### **Benefits for Peers Providing Services**

Peers working as peer support workers have reported increased confidence in their abilities, increased ability to cope with their own illness, and increased self esteem, sense of empowerment and hope (Repper & Carter, 2011; Solomon, 2004). These findings are not surprising as the identified benefits are not dissimilar to those experienced by most people who work in an occupation that is perceived as valued and enjoyable.

### **Service System Benefits**

Benefits have been reported for service delivery systems as well. Other professionals working along side peer providers see them functioning successfully and have increased respect for their peer workers, and stigma, negative attitudes, values and beliefs that many professionals continue to have about people with serious mental illnesses can be dispelled (Repper & Carter, 2011; Solomon, 2004). Longer lengths of community tenure and shorter hospitalization stays may equate to reduced costs for the system and these monetary benefits of utilizing peer support services may produce overall health care savings and contribute to the overall ability of the service system to meet the needs of the community (Davidson, Bellamy, Guy & Miller, 2012; Solomon, 2004).

## Implementation Considerations

The U.S. Department of Health and Human Services' Centers for Medicare and Medicaid Services now reimburses for peer support services delivered by peer providers. As of the publication of this curriculum, thirty-five states receive Medicaid reimbursement for these services (Insidehealthpolicy.com, 2014). Many other states also provide peer support services within their mental health systems and do so without federal reimbursement.

In order to be eligible for Medicaid reimbursement, states must meet several criteria related to training and supervision requirements. States have flexibility in how they meet these criteria, but competency must be assured (U.S. Department of Health and Human Services, 2007). In order to meet the Medicaid requirements, several states have adopted versions of the Certified Peer Specialist (CPS) training program. These training programs address topics that are important for implementation of peer support services such as communication skills, group facilitation, recovery planning, illness management, confidentiality, dual relationships, and other areas that peer support workers need to perform well. Not all peer support workers are Certified Peer Specialists and those providing peer support services have various titles including peer provider, peer support worker, peer specialist, etc.

Some of the most difficult issues faced by service providers and peer support providers relate to confidentiality, boundaries, and dual relationships. A variety of reasons contribute to the difficulties encountered including the fact that the community of people with serious mental illnesses is usually a small one, even in relatively large cities. Peer providers are usually acquainted with, or are friends of consumers that they also have a professional relationship with, and the peer provider and the consumer may also be in educational or treatment groups together. Another contributing factor is that mental health agencies often do not understand the issues involved and fail to provide suitable training and adequate supervision for peer as well as non-peer provider staff (Gates, Mandiberg & Akabas, 2010).

In addition to the topics noted above, there are also administrative issues that must be addressed such as hiring requirements, adequate pay, training, supervision, creating an accepting environment, gender and cultural issues, etc.

Although not easily differentiated, these topics are divided into two categories for this discussion, personal issues and administrative issues. The topics below are also discussed in several of the required readings. See for example, Davidson, Bellamy, Guy & Miller, 2012; Repper & Carter, 2011; Salzer & Mental Health Association of Southeastern Pennsylvania Best Practices Team, 2002.

### Personal Issues

#### *Confidentiality*

As mentioned, in small communities, and often in large cities, persons with lived experience of serious mental illness know one another – it is a small community of people

that can be fairly close knit. Thus, when one person becomes a peer support worker working within the mental health system, there can be cause for concern about sharing of information.

### *Role Identity and Boundaries*

One of the essential elements of the peer support relationship is the peer support worker's disclosure of his or status as a person with lived experience and the sharing of information about how he or she has learned to cope, make progress in recovery, and deal with various situations as they arise. This sharing of one's self is critical to the relationship and yet creates boundary issues due to the fine line between being someone who discloses information about his or her own illness and struggles, and is at the same time, a helping professional.

For example, peer supporters often find themselves in the same social milieu (e.g., at the same drop in center, or at the same social gathering) as current or former consumers with whom they have worked, or are working, and this presents considerable confidentiality and boundary concerns. In such cases, confidentiality needs to be respected but at the same time, the peer supporter needs to demonstrate friendliness and model good social skills while not disclosing the nature of the professional relationship. This can be especially difficult if the service recipient and peer support worker are known to have been friends for some period of time. As with other mental health professionals, considerable skill and ongoing supervision are important for peer support personnel.

Ideally, supervision of peer support personnel would be provided by trained and experienced peer support personnel. Presently, there are not national standards for training or supervision and this can limit the availability and suitability of supervision possibilities. Where trained, experienced peer support supervisors are available, they should be utilized to provide on-going supervision.

### *Dual Relationships*

Relatedly, the issues of sexual partnerships and developing friendships, can be very difficult, again because of the closeness that develops when two people share very personal and sometimes intimate details of their lives. There are some very difficult questions that should be discussed openly including the following:

- How should existing friendships be handled? Should they be maintained when working in an agency that provides services to the friends of peer workers?
- How can peers succeed in being "friendly" toward their clients without actually becoming friends with them? Regardless of its importance to the agency, is this a distinction that even makes sense to the clients?
- Can peer staff accept reciprocal support offered to them by the people they serve? If not, then does this not move them closer to behaving and functioning like non-peer staff?

Like all mental health staff, peer support personnel work in a position of trust with vulnerable people. Although friendships can sometimes develop this is often discouraged but may have an impact on a consumer who wants to develop or maintain a friendship with the peer support worker and does not understand the professional role and boundary issues of the peer support worker. As with all other mental health staff, sexual relationships between peer supporters and consumer clients are unethical and are not permitted. As with all mental health staff, supervision is critical to assisting peer support staff to navigate through these and other difficult situations.

## **Administrative Issues**

### *Hiring Requirements*

Although training in communication skills, confidentiality, dual relationships, etc., is unquestionably necessary, there are currently no federal standards regarding what is required and there are no standard education or previous experience requirements or recommendations that are recognized nationally. The InterNational Association of Peer Supporters (iNAPS) has developed a training curriculum for peer specialists as part of the U.S. Substance Abuse and Mental Health Services Administration's (SAMHSA) Recovery to Practice initiative (the initiative that funded development of this APA curriculum). Additional information can be obtained from the iNAPS website at [www.inaops.org](http://www.inaops.org).

While there are no national standards at this time, most agree that peer support personnel should receive training in communication, confidentiality, issues around dual relationships, working with trauma survivors, disclosure, provision of education and support, etc. Mental health managers and administrators also need training to understand the difficult situations that arise for peer support workers. As mentioned, on-going supervision is essential for all mental health staff, regardless of their professional training or experience.

### *Adequate Compensation*

Other administrative issues revolve around the tasks that some peer support staff are asked to perform and compensation received for work as a peer support worker. In many mental health systems where peers are employed, peer support workers receive minimum wage or just slightly more than minimum wage. Partly this is because many peer support workers do not have formal education beyond the high school level and partly it is because of the sub-professional tasks that they are often asked to perform in addition to their peer support duties. Peer support personnel are frequently asked to carry out tasks that support other staff and that are usually thought of as secretarial or support tasks, such as transporting clients, arranging meetings, etc. This is demeaning and these duties detract from the essential role of a peer support worker. The practice of treating peer support workers as sub-professional workers should not be acceptable or tolerated. As might have been observed from the discussion of the personal issues noted above, peer support work can be very difficult: emotionally draining, clinically challenging, and personally difficult. Peer support personnel need to be adequately compensated based on the difficult nature of the

work they perform rather than on the education and experience qualifications they bring to the position. Mental health managers and administrators need to be informed and receive training about the difficult nature of peer support work so they can appropriately address these issues (Gates, Mandiberg & Akabas, 2010).

#### *Cultural Competence, Gender Considerations, and Trauma*

The issue of matching clients with peer support workers based on gender and or racial or ethnic background is one that requires an open discussion with each client, the peer support worker, and the supervisor. There are times when such matching may be desirable but there can also be times when it would be better for the client and the peer support worker to experience a broader range of cultural and gender backgrounds. There is no generally accepted practice at present and each situation will require a discussion about the potential benefits and challenges of each scenario.

The issue of trauma is considerably different, and extremely important and complex. Due to the essence of peer support work, i.e., sharing of one's personal experiences, an important consideration is matching peer supporters with consumer clients by gender, especially where either the client or the peer support worker has been abused and suffered trauma. Good supervision by a well-trained clinician who can be of help to both the client and potentially the peer support worker is essential.

First and foremost, where a client has been abused by a member of the opposite gender, assignment to a peer support worker of the same gender as the abuser would not be appropriate. At the same time, provision of trauma services by an expert clinician is critical and should be part of every mental health service delivery system (a thorough discussion of these issues is provided in the Interventions III module of this curriculum). Similarly, it would be important to ensure that a peer support worker who experienced abuse has worked through those experiences sufficiently to maintain his or her own stability and be of help to a client from the gender of the abuser.

Relatedly, a peer support worker who has experienced severe trauma may not wish to, or be able to support another person when discussions about the trauma experience come up, which will likely happen even though the peer support process is not a clinical treatment process. This is an important issue that should be discussed openly with the peer support worker each time a new assignment of a client is to be made. Where a peer support worker believes it would risk his or her mental health stability if assigned a client with severe trauma, assignment of the new client should be made to a different peer support worker. It cannot be overstated that clinical services to work through trauma, provided by highly trained clinicians, should be available to all who need them.

Given that abuse and trauma have been experienced by many with serious mental illnesses, this is an issue that will likely come up frequently and must be addressed openly and sensitively in order to avoid re-traumatizing those involved. As stated, expert clinical services and supervision are essential.

### *Creating an Accepting Environment*

A question that was raised several years ago when the concept of peer support services was initially introduced, and would still be raised by those resistant to the idea of employing people with lived experience as providers of service, is whether or not such services have a detrimental effect on users of the service. Consistently, studies have found that using peers to provide services, either traditional services such as case management or peer support services, did not have a detrimental effect on the person being served (Davidson, Bellamy, Guy & Miller, 2012; Davidson, Chinman, Sells & Rowe, 2006; Repper & Carter, 2011; Rogers, Kash & Brucker, 2009; Solomon, 2004) and in fact, consumers consistently report that they highly value the service. These findings are robust and should dispel any doubts that might remain about the viability of using peers to provide peer support or traditional mental health services.

Despite these robust findings, considerable resistance remains with regard to hiring people with lived experience into the mainstream of the treatment setting. As Davidson and colleagues (2012) point out, this resistance takes several forms including questions about possible stress related relapse, ability to handle the workload, etc. Existing staff may have many legitimate questions and these should be discussed openly. Clinicians can be worried about losing status or working alongside, and as an equal with, a person they may have treated not so long ago, or may still be treating. However, questions about the possibility of relapse, stress, etc., are discriminatory and are no more acceptable than they would be if an individual with a physical illness were being considered for a staff position and such questions were raised.

Discussing the questions and concerns that existing staff have is an important step toward creating an accepting environment where concerns can be raised by all involved staff, including peer support workers once they join the team. Ensuring open communication and appointing a senior member of the staff who will support and champion both the concept and the peer support workers can also facilitate acceptance by less senior staff.

### *Adequate Supervision*

An important component of the plan for adding peer support personnel is to ensure that provisions for adequate supervision are in place. Considering the very challenging work that peer supporters do and the fact that they themselves have serious mental illnesses, adequate support and supervision may be one of, if not the most important component for success. As mentioned, every effort should be made to have supervision provided by experienced peer support personnel rather than by non-peer clinicians or managers. Where issues related to trauma are concerned, both highly trained clinicians and peer support supervisors may be needed.

## Challenges

The challenges associated with provision of peer delivered services, principally peer support services offered within mental health service systems, are twofold: 1) how to conduct research to determine the efficacy of this rapidly expanding service with service/program models that frequently overlap with one another and or combine elements of different models, and 2) how to resolve the many difficult implementation issues that can hinder provision of the service.

With regard to the first challenge, people with lived experience of shared mental health problems consistently report that having the support and help of peers as they move through the recovery process is one of the best and most important components of their treatment experience. For this reason, it is important to determine the impact of peer support on treatment outcomes, but this has been difficult to do, in large part because the models of peer support are rarely “pure”. That is, they tend not to follow any prescribed protocol, making comparison among and between them and other services difficult. Even the term “peer support” is not used consistently in the literature, and does certainly not denote a consistent service model in practice. The practice is further complicated by the lack of standardization in education and training requirements, as differing levels of these background characteristics could influence the delivery of services and impact on service recipients.

With regard to the second challenge, the many unresolved administrative issues surrounding this relatively new service need urgent attention if the practice of peer support is to move forward as a respected service. Training needs to be standardized and education and experience requirements need be settled in order for the practice to gain legitimacy as a respected component of the service delivery system. Peer support workers need to be compensated adequately – minimum wage does not seem to be appropriate remuneration for individuals who must face, and resolve successfully, so many tremendously difficult issues. The situations peer support workers find themselves handling are as challenging, and perhaps even more so, than those faced by the average mental health practitioner. Figuring out how to compensate peer support personnel adequately – possibly on par with highly educated professionals – is a significant challenge indeed.

Adequate compensation is but one of the administrative challenges that need to be overcome. Issues around trauma of clients and peer support workers alike are extremely complex, important, and challenging. Clearly stated duties, deliverables, and expectations should be required components of the job description for peer support personnel. Overcoming the resistance from managers, clinicians, and others in the service delivery system will happen over time and possibly only when many of the other issues are resolved. However, given the importance users of the service system attach to the service, this would seem to be an important undertaking that needs to be attended to with some urgency.



## Summary

In summary, peer delivered services, and in particular peer support services, are highly valued by people receiving services for serious mental illnesses. Benefits for people receiving the service have been shown, and peers delivering the service have reported that engaging in the provision of peer support is beneficial to them.

There are however, several challenges that must be overcome if peer delivered services, particularly peer support services, are to become a respected component of mainstream mental health service delivery systems. Given the rapidity with which the concept of peer delivered service has grown, the move to implement various forms of the service into service delivery systems, and the lack of standardization of hiring requirements, training, status, etc., fairly urgent attention should be given to resolving the difficult implementation issues that could ultimately hinder the successful integration of peer support services into service delivery systems.

## Sample Learning Activity

The leaning activity is a role play situation. If the group is large, it should be divided into two smaller groups of about six or persons each. The consumers in the group will lead the activity.

Each of the participants will play the role of a professional in a mental health center and one participant will play the role of a consumer. There will be a psychologist, social worker, psychiatrist, nurse, occupational therapist, and recreational therapist plus a consumer. If there are not enough participants, one or two of the professional roles should be eliminated.

The situation is as follows. The psychologist has suggested that a peer support program should be initiated. The other disciplines are opposed. Some are afraid they will lose their professional status, some worry that they will not know how to work with individuals who have serious mental illnesses and who are professional co-workers, others believe that peer support workers will be vulnerable to becoming ill and this will create work flow problems. Other beliefs may come out as well.

All are to espouse their viewpoints and argue for their particular point of view, indicating why they feel as they do. The psychologist is to put forward opposing arguments to convince the others that starting a peer support program is the right way to go. The consumer is to state why he or she believes the new program will be beneficial for consumers.

Following the role play, the group is to process the feelings that they had and discuss their true beliefs about peer support programs and the role of peer support personnel within mental health service systems.

## Sample Evaluation Questions

### Question

### Correct Answer

1. The following are current models of peers working in peer delivered services:

- a) mutual support group leaders
- b) warm line providers
- c) case managers
- d) peer support workers
- e) all of the above
- f) a, b, and d above

e is correct

2. Several essential elements of peer support are:

- a) individuals are current or former users of the mental health system with lived experience of serious mental illness
- b) individuals disclose their status as people with serious mental illness
- c) the peer supporter offers “conditional regard” for people he or she works with
- d) all of the above
- e) none of the above

d is correct

### True

### False

3. True peer support relationships are ones where the peer supporter receives as much support from the person he or she is supporting as the consumer client because the relationship is one of reciprocal support

F

4. Research has consistently demonstrated that there are significant differences in outcomes associated with provision of peer support services, including better employment, housing, and recidivism rates for consumers who have received peer support services

F

5. Peer support workers face considerable challenges with respect to navigating issues such as dual relationships, friendships and boundaries, etc., but they are compensated appropriately as professional members of the treatment staff and should be respected as full members of the treatment team

F

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## **Additional Resources**

American Psychological Association Recovery to Practice Initiative.

<http://www.apa.org/pi/rtp>

InterNational Association of Peer Supporters. <http://www.inaops.org>

Salzer, M. S., Baron, R. C., Menkir, S-M A. & Breen, L. (2013). Community integration practice: Promoting life in the community like everyone else. In P. Nemeč & K. Furlong Norman (Eds.). *Best practices in Psychiatric Rehabilitation*. Columbia, MD.: United States Psychiatric Rehabilitation Association.

## Citing the Curriculum

Citation for this Module:

American Psychological Association & Jansen, M. A. (2014). Peer Delivered Services. *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

Citation for the full Curriculum:

American Psychological Association & Jansen, M. A. (2014). *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

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# American Psychological Association

## Recovery to Practice Initiative Curriculum: Reframing Psychology for the Emerging Health Care Environment

### *14. Systems Transformation*

August 2014

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## Overview

This module presents information about the steps and ingredients necessary for transformation to a recovery oriented system. The challenges involved in such efforts are presented along with information about components of successful transformation efforts.

## Learning Objectives

At the end of this module you will be able to:

- List the eleven key ingredients necessary for system transformation
- Identify and discuss five reasons that contribute to the complexity of transformation efforts
- Discuss four components of a measurement feedback system
- List and discuss three steps that psychologists can take to lead transform efforts

## Resources

- Lecture Notes
- Required Readings
- Lecture Notes Citations
- Sample Learning Activity
- Sample Evaluation Questions
- Additional Resources

## Required Readings

Davidson, L. Tondora, J., O'Connell, M. J., Kirk (Jr.), T., Rockholz, P. & Evans, A. C. (2007). Creating a recovery-oriented system of behavioral health care: Moving from concept to reality. *Psychiatric Rehabilitation Journal*, 31, 1, 23–31.

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## Activities

Complete the following activities:

- Read the lecture notes
- Read the required readings
- Engage in a learning activity related to this module
- Evaluate students' understanding of this module.

## Lecture Notes

People with lived experience of serious mental illness are strongly encouraged to be part of the delivery of the curriculum including being active participants in the delivery of the lecture. Refer to the curriculum Instruction module for additional information.

### Introduction

Following recognition that people with serious mental illnesses can and do recover, some mental health systems began taking steps to transform so that they could provide the kind of assistance to help people achieve their identified goals. Subsequently, the publication of government policy documents such as the Surgeon General's Report (U.S. Department of Health and Human Services, 1999), the Institute of Medicine's Crossing the Quality Chasm report (2001), and the Report of the President's New Freedom Commission on Mental Health (2003) provided greater impetus for these efforts. Also, research on services that help people learn the skills they need to achieve their goals has resulted in identification of practices known as evidence based practices (EBPs) and promising practices. Taken together, these developments have spurred considerable interest in transforming systems to ones that are truly oriented toward providing the kinds of services needed in an environment that promotes the values of recovery for people with serious mental illnesses.

However, transforming a mental health system or an organization to one that is focused on helping people recover requires a fundamental paradigm shift in thinking and acting. This shift involves moving from a system that is provider driven to one that is driven by the individuals who use the system and their families. It means embracing the recovery philosophy of full partnership with consumers and their families, and accepting that individuals will choose the services they need to help them achieve the goals they have for a satisfying life. It also involves providing the kinds of services that have been shown to work and those that show promise of achieving desired results (Davidson, O'Connell, Tondora, Styron & Kangas, 2006; Farkas & Anthony, 2010; Torry, Drake, Dixon, Burns, Flynn, Rush, Clark & Klatzker, 2001; Wilkniss & Corrigan, 2011). This has proven to be more difficult than originally hoped, and while there have been some successes, generally speaking, little change has actually happened (Hogan, 2010). As Hogan pointed out:

Most people with schizophrenia get no or virtually no care, little of the care is delivered consistent with the best evidence, and people with schizophrenia are overrepresented in most of life's worst circumstances: Incarcerated, homeless, disabled, or dying early (p. 104).

Within mental health systems, there are some elements that have been identified as facilitating recovery from serious mental illnesses and some elements that have been identified as hindering recovery. These are displayed in the table below:

<b>Hinders Recovery– Organizational Culture &amp; Structure</b>	<b>Helps People Recover - Organizational Culture &amp; Structure</b>
Culture and Organization that is Pathology-Focused/Illness-Focused/Dominance of Medical Model	A Recovery-Oriented System with a Vision of Recovery/ Extending Support beyond Traditional Boundaries/ Consumer-Driven
Lack of Change & Innovation	Encourage Innovation/ De-fund or Transform Ineffective Practice & Programs
Lack of Holistic Orientation (e.g., neglect spirituality, physical health)	Holistic Approach/ Proactive Approach supporting Preventative Measures/Positive Mental Health
Access Limited to Those in Crisis	Multiple Strategies
System Promotes Dependency/ Paternalism & Maternalism	Self-Responsibility/ Fostering Growth & Interdependence/ Assistance with Letting Go of Dependency on System
Stigma within the System	Fully Committed to Consumer Voice/ Support Risk Taking/ Freedom to Fail
Social Segregation	More Tolerance for Diversity & Unusual Behavior
Funding Problems	Adequate Funding and Equitable Distribution of Resources/ Monies Reinvested in Community/ Voucher System
Lack of Consumer Voice on Personal and System levels	Consumers Employed Within System at All Levels/ Consumers Involved in Decision-Making Processes Such as Staff Hiring & Firing/ Mandated Consumer Positions on Boards & Committees/ Office of Consumer Affairs/ Ombudsman Program

*Onken, Durmont, Ridgway, Dornan & Ralph, 2002*

Change can be accomplished however, and this is one of the challenges presently confronting the mental health community. Psychologists with knowledge of the recovery paradigm are ideally suited to take up this challenge and serve as leaders of system transformation.

### **Organizational Transformation: Moving Mental Health Services to a Recovery Orientation**

Transforming mental health systems to ones that are focused on helping people recover and gain or re-gain their functional potential is increasingly recognized as one of the most

important undertakings in the field and one that requires collaboration among all stakeholders (Piat, Sabetti & Bloom, 2010). As stated by Wilkniss & Corrigan (2011):

It is widely acknowledged by mental health authorities, providers, researchers, consumer/survivors and families that recovery and EBPs are among the most important service improvement initiatives in modern psychiatry...They are essential to bridging the “quality chasm” in health care in the U.S. (p. 322).

Achieving a transformational shift in the way services are provided to people with serious mental illnesses and in the services that are offered is a difficult and complex undertaking. Accomplishing such a shift involves many elements including changing the culture of the organization, re-allocation of resources available, ensuring that individuals such as administrators and providers are in full agreement with the changes, conducting evaluations to document benefits of changes, and implementing billing and other procedures that require adherence to new models. Everyone must be fully informed, committed, and willing to put necessary procedures in place to ensure sustainability. And, all must be able to work in synergy to ensure that the system functions in an integrated and coordinated fashion.

In a report commissioned by the U.S. Agency for Healthcare Quality and Research, the authors noted the difficulty of changing systems:

Despite recent efforts to improve the quality of care for this diverse group, vexing challenges remain. These include the difficulties of changing the focus of care from acute symptom control and relapse prevention to long-term, recovery-focused care, coordinating care among different providers, and adapting interventions to different settings with multiple, fluctuating funding streams (Green, Estroff, Yarborough, Spofford, Solloway, Kitson & Perrin, 2014, p. xi).

These same authors referred to an IOM report (Institute of Medicine, 2006) which provides a framework for such change:

The [IOM] report recommends that organizations promote patient-centered care in several ways. First, they should incorporate informed patient-centered decision making with active patient participation in design and revision of treatment and recovery plans, use of psychiatric advance directives (PADs), and provision of information on the availability and effectiveness of treatment options. Second, organizations should adopt recovery-oriented and illness self-management practices that support individuals’ preferences for treatment (including medications), peer support, and other elements of a wellness recovery plan. Third, organizations should maintain effective formal linkages with community resources to support service users’ self-management of illness and recovery (Green, Estroff, Yarborough, Spofford, Solloway, Kitson & Perrin, 2014, p. S4).

## Eleven Key Ingredients for Systems Change

Virtually everyone who has written about mental health transformation efforts has identified several key ingredients that must be in place for this to come together, including:

- Strong and active leadership that is committed to the philosophy, values, and practice of recovery
  - Requires a leader who understands the recovery paradigm and is committed to seeing change happen
- Ability to link the new system to the organization's priorities and mission
  - The new direction cannot be isolated from or in opposition to the values and mission of the existing organization
- A reorganization that is system-wide, rather than one that is conducted piecemeal
  - Change requires a total vision rather than bits and pieces that crop from time to time
- Commitment to a long term process
  - Systems change will not happen overnight – leaders must be willing to see the process through and work with successes and setbacks
- Willingness to collaborate with all stakeholders: policy makers, providers, consumers, families, educators, those in the forensic system, and professional associations
  - The entire community must be involved, their opinions respected, and all must feel their particular needs are attended to
- Ability to put structures in place that will ensure the continuation of the initiative even after current leadership changes
  - Leadership change is frequent and many change efforts fail when new leaders arrive with different priorities. Top management that is onboard along with budgetary structures that are supported are needed
- Willingness to develop consumer and family leadership
  - Political advocacy by service users is critical for successful change
- Commitment to hiring the right people and to providing initial and ongoing training and supervision
  - Professionals and peer service providers that have the right training are essential
  - Ongoing supervision of all staff must be part of the commitment to ensure the transformation takes hold



- Provision of the most appropriate services and fidelity in implementing evidence based and promising practices

Providing traditional services under a new name is not system transformation

Without fidelity to those services that are evidence based, outcomes will not be achieved and the transformation effort will likely fail

- Conduct of outcome measurement and gathering of feedback

Resources to gather and analyze data are crucial in order to document the effect of the changes

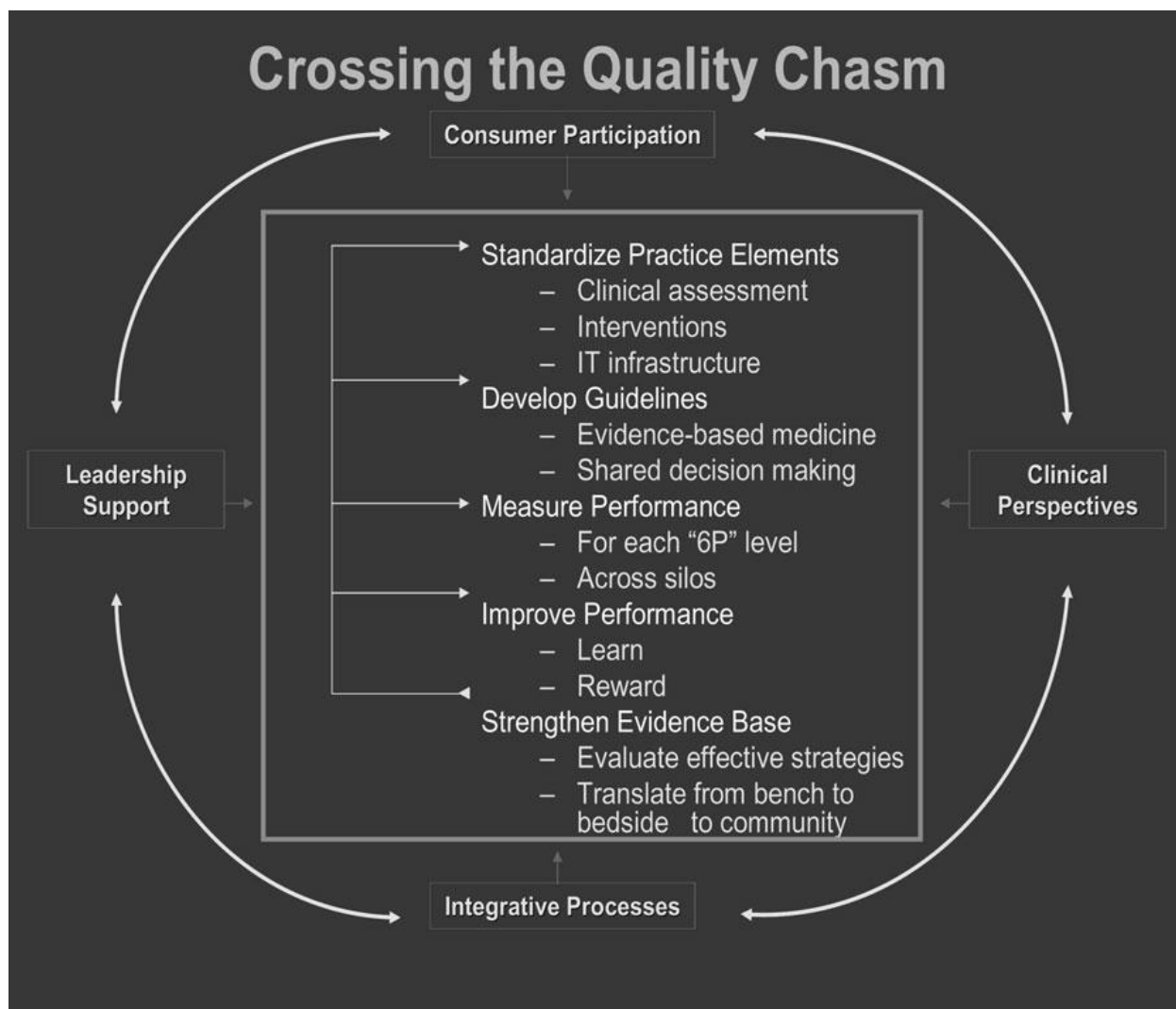
- Willingness to make changes based on measurement and feedback

Results of the outcome measurement system and feedback must be viewed objectively and utilized to make further changes – this demonstrates true leadership and willingness to continue practices that are working while discontinuing those are not (Bickman, 2008; Clossey & Rowlett, 2008; Davidson, O’Connell, Tondora, Styron & Kangas, 2006; Epping-Jordan, Pruitt, Bengoa & Wagner, 2004; Farkas, Ashcraft & Anthony, 2008; Jacobson & Curtis, 2000; Kendall, Muenchberger & Catalano, 2009; Mancini, Moser, Whitley, McHugo, Bond, Finnerty & Burns, 2009; Morris, Day & Schoenwald, 2010; Olmos-Gallo, Starks, DeRoche Luszczakoski, Huff & Mock, 2011; Piat & Sabetti, 2009; Rosenheck, 2001; Torrey, Drake, Dixon, Burns, Flynn, Rush, Clark & Klatzker, 2001).

When implementation of EBPs has been specifically studied, research has found the same key ingredients, specifically, committed leadership, allocation of sufficient resources, an organizational culture that embraces innovation, fidelity to the practice, careful hiring procedures, and effective training and supervision (Mancini, Moser, Whitley, McHugo, Bond, Finnerty & Burns, 2009; Whitley, Gingerich, Lutz & Mueser, 2009).

The following diagram from the 2001 Institute of Medicine’s Crossing the Quality Chasm report notes many of the essential elements for systems change:

## Crossing the Quality Chasm



Source: Institute of Medicine, 2001

At the end of the day, it is widely recognized that we have a responsibility to transform the way that mental health systems operate. Accomplishing the transformation has been difficult however. According to Morris, Day & Schoenwald (2010):

...consumers of mental health and substance use conditions treatment and other human services recipients have a right to expect that the services they receive are the best possible — that they actually work. Public systems have a special responsibility to purchase services that work, as the resources for safety net programs are chronically limited. We believe that interventions supported by rigorous research offer more reassurances of that level of quality... Why would a provider organization consider modifying practice?... The bottom line here is matching the needs and choices of consumers/persons in recovery/service recipients to services that will yield the desired

outcomes – the ethical responsibility of providers to give the best possible care desired by the service recipients who are their partners in care (pp. 2-3).

## **Obstacles**

As if the list of key ingredients were not daunting enough, each of the items in the list is quite complex as each contains several components that are required. As just one example, in order to gain commitment from a system or an organization, the leadership must truly understand what the principle of recovery means and what is involved in moving to services that have been proven to work for people with serious mental illnesses. This means that they must be willing to partner with consumers, their families, and other stakeholders in a truly collaborative manner. The leadership must also know how to begin and carry through with the change process and they must understand the need to reallocate budgetary resources, commit to hiring and training appropriate staff, and commit to conducting outcome evaluations and garnering feedback in order to make further change.

Another key hurdle is that of changing long established practices in the health care arena, especially those that challenge the medical model and providers' traditional ways of thinking about their roles. This can be especially challenging when providers see a recovery oriented system as threatening to their professional status rather than viewing it as an exciting opportunity to work in partnership with people who are working to make life changing decisions. All of the potential hurdles need to be thought about thoroughly and discussed with all stakeholders before the change process is initiated.

When the complex and difficult nature of such a change is coupled with the realities of most mental health systems, it is easy to see why change has proceeded slowly. In most organizations and systems, there is frequent turnover of leadership, continual threats to ever dwindling resources, and provider resistance to change that is often seen as a threat to provider autonomy (Clossey & Rowlett, 2008; Rosenheck, 2001). Moreover, many believe that in most parts of the U.S., there is no mental health system, but rather a set of fragmented and uncoordinated services that most people with serious mental illnesses reject (Drake & Essock, 2009; Institute of Medicine, 2001; Institute of Medicine, 2006; President's New Freedom Commission on Mental Health, 2003).

Many who have written about the need to transform the mental health service delivery system note that simply providing information about the fact that people recover from serious mental illnesses or educating providers about evidence based and promising practices will have little impact. It is widely acknowledged that changing a system is a long term endeavor that requires sustained commitment from leaders who understand the values and practices to be implemented and who know how to undertake and maintain a systematic change process (Clossey & Rowlett, 2008; Epping-Jordan, Pruitt & Bengoa, 2004; Farkas & Anthony, 2010; Torry, Drake, Dixon, Burns, Flynn, Rush, Clark & Klatzker, 2001). It has also been recognized that managers must be willing to put forward clear expectations

with incentives for those who adopt the new values and practices and sanctions for those who obstruct the change process (Morris, Day & Schoenwald, 2010).

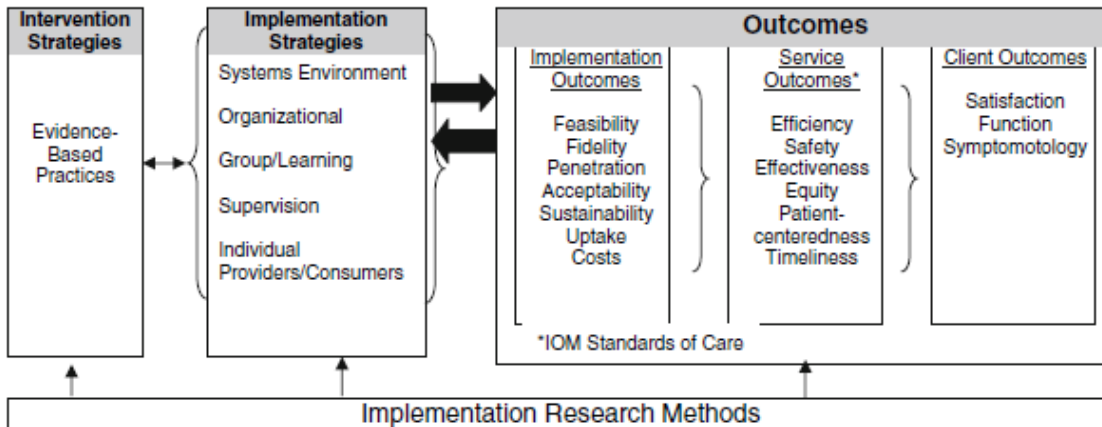
Change is not easy for most individuals and is certainly difficult for entire systems, which are almost without exception inert and difficult to move. Professionals within the system are usually highly resistant to change because they do not want to give up the ways they have been conducting business – after all, they have been providing services that they believe are the right ones to offer and likely even believe they are effective (Clossey & Rowlett, 2008). Frequently, the more influential the professional, the more resistant to change due to the perception that the status quo will change and power will be lost. When high turnover rates among administrators are added, initiating and sustaining change, can be extraordinarily difficult.

In order to meet the needs of all those in the system with serious mental illnesses, it is important that transformation efforts encompass the entire system and include all necessary interventions in a recovery oriented perspective (see the three Interventions modules in this curriculum) to achieve a comprehensive system (Farkas & Anthony, 2010; Rosenheck, 2001). This generally means that all professionals will need to make changes to the ways they deliver services and the ways decisions are made.

### **Implementation and Sustainability**

Changing a system to be one that respects a person's capability to recover (implementation) and ensuring that the system remains recovery oriented (sustainability) has proven to be considerably more difficult than originally hoped and some have begun to call for implementation research to identify solutions to the difficulties experienced and to enable the U.S. to gain the benefits of research dollars invested in identifying services that work (Insel, 2007). In response, the federal government has initiated a research agenda to promote research based solutions for transformation efforts (Institute of Medicine, 2001; U.S. Department of Health and Human Services, 2006). The model depicted below has been proposed as one way to view the effort to measure the effect of monitoring implementation results (Proctor, Landsverk, Aarons, Chambers, et al., 2009).

## Conceptual model of implementation research



Source: Proctor, Landsverk, Aarons, Chambers, Glisson & Mittman, 2009

A critical first step is assessing the recovery attitudes, vision, and status of the various stakeholders in the system. These include people using mental health services and their families, providers, administrators and managers, and any others that have a stake in the system. Self assessment tools for various stakeholders have been developed to enable system-wide assessment and these are available at <http://www.ct.gov/dmhas/lib/dmhas/publications/practiceguidelines.pdf>.

The key strategies necessary to transform services are those needed to ensure sustainability and include:

- Developing coalitions and providing the members with decision-making authority
- Ensuring that changes are linked to existing goals and values
- Conducting quantitative monitoring of implementation and performance on a continual basis
- Hiring the right kinds of people and providing continual training opportunities and expectations that become self-sustaining
- Adapting new services to special needs of individual communities, and
- Ensuring that knowledge gained from the implementation research effort is disseminated so everyone concerned knows how the effort is progressing (Bickman, 2008; Morris, Day & Schoenwald, 2010; Rosenheck, 2001).

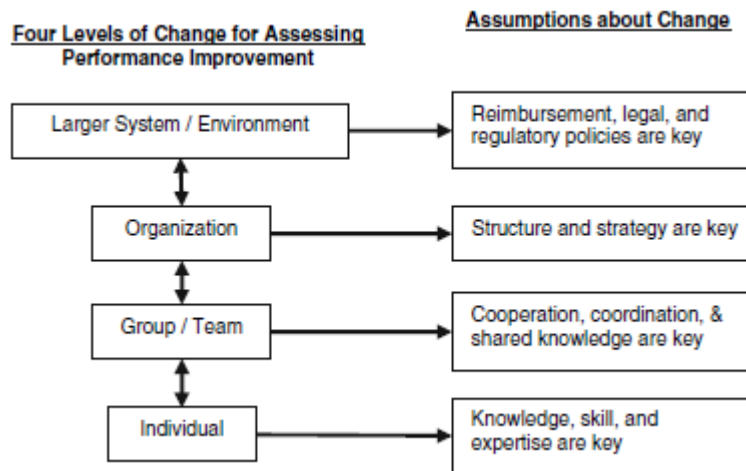
An essential component that can easily be overlooked is a measurement system that provides feedback on fidelity to services (where established fidelity scales exist) and also collects data on progress being made. Measures should be administered frequently; collecting information once a year will not produce information that can inform real time processes and effect change as needed. The feedback system must also be more than a questionnaire that providers fill out – such a strategy will result in providers indicating that

great progress is being made. One such system includes feedback on clinical processes, the environmental context in which the clinical interventions take place. This would encompass the values of the providers and organization and measure their relation to recovery oriented philosophy and outcomes, i.e., are real life changes taking place in the lives of people that are receiving services (Bickman, 2008). Evaluation data should be channeled to a continuing needs assessment system to ensure that new services are appropriate for the needs of the particular system. Feedback to administrators, clinicians and consumers along with willingness to change where results indicate that something is not working, are critical for effecting meaningful change to the service system as it evolves.

Another obstacle emerges even when changes are accomplished. Sustaining new practices can be a real challenge especially in light of the fact that many health care administrators (those with decision making authority) do not understand mental health consumers or the services they need. With continual budget cuts and the high level of frequent leadership and staff changes that occur in health care systems, it is all too easy for newly appointed administrators to dismantle a recovery oriented system and return to the more familiar medical model, which often has support from medically oriented professionals. This is where a strong measurement system that demonstrates positive outcomes and cost comparisons with cost benefits accrued from the new system, can save the day and avoid reverting to the old ways of doing business. Providing examples of what is working and the successes that have been achieved will provide encouragement and reinforcement for change efforts and help maintain enthusiasm for the process.

A graphic depiction of how sustainability can be assessed can be seen below:

### Sustainability Levels for Assessment and Assumptions



Source: Shortell, 2004

### Psychologists Have an Important Role to Play

Due to their broad training in clinical services, research, program evaluation, and organizational systems development, psychologists often advance to leadership positions in

mental health systems. In this rapidly advancing era of health and mental health reform, it is crucial that psychologists be informed about the essential elements of a recovery oriented system and about the full range of services that people with serious mental health can benefit from so they can effectively lead transformation efforts. Full engagement with all modules of this APA recovery oriented curriculum is an important first step in the training of psychologists for these new leadership roles. It is equally important that psychologists understand the complexities of the transformation process and be willing to undertake the thoughtful and difficult work needed to bring about change, implement new services correctly (with fidelity), and in a sustainable fashion by taking the steps needed to ensure that the new system can be maintained. Psychologists are leaders in effectiveness research and demonstrating the effectiveness of a new system is essential to garner funding and support. The key ingredients discussed in this module provide the guidance for psychologists to undertake change efforts, but psychologists must be thoughtful and politically savvy about the work they undertake. They must also be willing to recruit others who will champion efforts to provide the services people with serious mental illnesses desire and to do the difficult work to maintain those services in the face of challenges that will inevitably arise.

### **Some Successes**

Despite the considerable challenges that the field has experienced, many states and organizations have taken steps to make services more recovery oriented and to offer services that are outcome based. The Substance Abuse and Mental Health Services Administration (SAMHSA) awarded transformation grants to states to encourage them to move forward with transformation efforts and is collecting information about transformation efforts through the National Outcome Measures initiative. Several states have made substantial progress toward this goal, notably among them Connecticut, Delaware, New York, Ohio and the city of Philadelphia.

Some of these successes have been documented. In Connecticut for example, in early 2000, Davidson and his colleagues were asked to assist the state with moving to a recovery oriented system of mental health care. With this commitment from the leadership, the team was able to lead a systematic initiative that targeted the state as a whole and developed a completely new approach to service provision which began with the critical step of assessment. The effort was designed as a several year approach with several interrelated steps:

- a) Developing core values and principles based on the input of people in recovery
- b) Establishing a conceptual and policy framework based on this vision of recovery
- c) Building workforce competencies and skills through training, education, and consultation
- d) Changing programs and service structures;

- e) aligning fiscal and administrative policies in support of recovery; and, finally
- f) Monitoring, evaluating, and adjusting these efforts (Davidson, Tondora, O'Connell, Kirk, Jr., Rockholz & Evans, 2007, p. 23)

The process and details of this successful systems change effort are detailed in the article by Davidson and colleagues, which is a required reading for this module.

An example of a successful local change effort is from Omos-Gallo and his colleagues who provided assistance to a mental health center in Denver whose leadership decided that the center should become one that is oriented to helping people recover the effects of their illness. The group described seven key strategies and identified challenges that were turned into opportunities. The changes described include:

- a) Vision and persistent leadership
- b) Consumer inclusion and involvement
- c) Seizing opportunities to add recovery oriented ideas into clinical practice
- d) Providing the right level of service at the right time
- e) On site staff recovery training
- f) Hiring the right people, and
- g) Outcome driven learning and quality improvement (Olmos-Gallo, Starks, DeRoche Luszczakoski, Huff & Mock, 2011, p. 1).

Several common elements can be seen from these examples and one that is a crucial first step is commitment from the leadership. Having leaders that understand the importance of moving to a recovery oriented system is essential. Partnerships among stakeholders including consumers and family members are key to the effort. Developing a competent staff is crucial. And, establishing, right at the very beginning, and using an outcomes monitoring system is an absolute must if the effort is to be sustained.

## Challenges

Changing long established practices in the health care arena, especially those that challenge the medical model and providers' traditional ways of thinking about their roles, presents a difficult hurdle. This is even more challenging when entire systems are involved such as large mental health systems. In the U.S., large systems are essential however since states are most often the source of funding for the majority of mental health services.

Threats to system change come from a variety of sources including provider misunderstanding of the recovery paradigm and associated services, lack of leadership and commitment, continually dwindling budgets, never ending changes in administrative leadership, and provider failure to properly implement services and develop outcomes monitoring systems to support sustainability of new services.



The complexity of the components that must be brought together to effect change can be daunting and even overwhelming. And, those undertaking such change efforts must have the political will, stamina, and be politically savvy if they are to succeed. Despite these challenges, mental health systems and the providers that work therein have a responsibility to do nothing less than to provide the most up to date services in an environment that encourages engagement and recovery.

## Summary

Transforming systems and organizations so that they focus on, and provide recovery oriented services is an ongoing challenge. While many systems and organizations have attempted to confront the challenges, and several tout their environment and services as recovery oriented, few have succeeded in changing the organizational culture and actual services provided in substantial ways.

Despite the considerable challenges that the field has experienced, many states and organizations have taken steps to make services more recovery oriented and to offer services that are outcome based. Several large systems have made substantial progress toward this goal, notably the states of Connecticut, Delaware, New York, Ohio and the city of Philadelphia. These efforts continue and with time, more of these efforts are successful. A notable achievement that is testament to the success of these efforts is the incorporation of peer services in many if not most mental health systems. While not a total transformation and while challenges remain with implementation of peer delivered services, the fact that consumers not only have a say in the kinds of services provided, but actually deliver those services in some case, is a testament to the fact that progress is underway. See the Peer Delivered Services module of this curriculum for additional information.

Several common elements necessary for successful transformation efforts can be seen from the examples presented. One that is a crucial first step is commitment from the leadership. Having leaders that understand the importance of moving to a recovery oriented system is essential. Partnerships among stakeholders including consumers and family members is key to the effort. Developing a competent staff is crucial. And, immediately establishing and using an outcomes monitoring system is a must if the effort is to be sustained.

This module reviews the key ingredients needed to effect change and notes the major challenges to transformation efforts. Psychologists' training prepares them for this specialized work better than most mental health practitioners. The research and evaluation capability that psychologists bring to their work makes them ideally suited for leadership positions as change agents.

Key ingredients include:

- Strong and active leadership that is committed to the philosophy, values, and practice of recovery

- Ability to link the new system to the organization’s priorities and mission
- A reorganization that is system-wide, rather than one that is conducted piecemeal
- Commitment to a long term process
- Willingness to collaborate with all stakeholders: policy makers, providers, consumers, families, educators, the forensic system, and professional associations
- Ability to put structures in place that will ensure the continuation of the initiative even after current leadership changes
- Willingness to develop consumer and family leadership
- Commitment to hiring the right people and to providing initial and ongoing training and supervision
- Provision of the most appropriate services and fidelity in implementing evidence based and promising practices
- Conduct of outcome measurement and gathering of feedback
- Willingness to make changes based on measurement and feedback.

Development of outcome measurement systems is an area of specialized expertise for psychologists, making it imperative that psychologists take on leadership roles in system change efforts.

The issue of sustainability has been summed up by Dixon (2014) in the introduction to a recent report:

...strong, supportive relationships—between clinicians and service users and among organizational staff at various levels—are the key to sustainable improvements in treatment and outcomes. Organizational practices and cultures that nurture such relationships are therefore critical, given the strong implication of this report that the therapeutic and recovery enhancing relationships between users and professionals/clinicians/providers are the essential—and most endangered—element in mental health services. Administrative, fiscal, and policy impediments to forming such relationships must be addressed rather than regarded as inevitable (p. v).

## Sample Learning Activity

This is a large group exercise. The full group is actively involved in all parts of the exercise.

For the first part of the exercise, the group is to spend several minutes thinking about and deciding on the changes that need to be made to the community mental health system in their hypothetical community. The current system in this community is comprised of an outpatient clinic which is oriented toward diagnosis, medication prescription, a case management program, social work staff that link individuals to community services, and some counseling services. There is also a hospital where people in acute crises are treated. Remember that for change to be effective, it should be system wide with all components (reference the eleven key strategies discussed in the module) considered rather than making changes in a piecemeal fashion. One member of the group should write down the things the group believes need to change on a board where they can be seen by all.

For the second part of the exercise, the group is to list all the categories of stakeholders that need to be involved. For example, the director of the system might be one, consumer representatives might be another, program managers might be a third, etc. These should be written on the board as well.

For the third part of the exercise, the group is to list the components of the system that will need to change in order to accomplish the vision for the new system. Examples could be that the intake and assessment process might change, the case management system could become more participatory, in-depth psychotherapy might no longer be offered in favor of CBT and skills training, etc. These are only examples – the group should identify the changes it believes are needed. As before, write these on the board.

For the fourth part of the exercise, the group is to answer the following two questions: Who will benefit from the proposed changes? Who will lose from the proposed changes? The answers to both questions should be written on the board under the headings: Beneficiaries and Losers.

For the fifth part of the exercise, the group should review the eleven key ingredients for effective change and determine which have been covered, which remain to be considered, and how the needed steps will be accomplished.

## Sample Evaluation Questions

### Question

### Correct Answer

1. The following are some of the key ingredients for system change:

- a) leadership commitment
- b) involving all stakeholders in partnerships that include consumers and family members
- c) hiring the right staff and providing ongoing supervision and training
- d) implementing services with fidelity
- e) commitment to long term process
- f) an outcomes monitoring system
- g) a, b, c, and f
- h) all of the above

h is correct

2. Some of the obstacles to system change include:

- a) failure to obtain commitment of key system leaders
- b) providers' lack of understanding of the recovery paradigm and effective services
- c) continual budget and leadership changes
- d) lack of attention to outcome measurement systems
- e) all of the above

e is correct

**True** **False**

3. The importance of implementing and using an outcome measurement system is that it helps to make changes as needed and can provide data on service outcomes and cost benefit comparisons

T

4. Psychologists' training makes them especially suited for leadership roles in mental health systems

T

5. Providing information about recovery from serious mental illness and educating providers about evidence based services is the most important component of the change process

F

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## **Additional Resources**

American Psychological Association Recovery to Practice Initiative.

<http://www.apa.org/pi/rtp>

Connecticut Recovery Practice Guidelines available at:

<http://www.ct.gov/dmhas/lib/dmhas/publications/practiceguidelines.pdf>

## Citing the Curriculum

Citation for this Module:

American Psychological Association & Jansen, M. A. (2014). System Transformation. *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

Citation for the full Curriculum:

American Psychological Association & Jansen, M. A. (2014). *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

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# American Psychological Association

## Recovery to Practice Initiative Curriculum: Reframing Psychology for the Emerging Health Care Environment

### *15. Scientific Foundations*

August 2014

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## Overview

In this module of the course we will discuss the issues surrounding research on recovery for people with serious mental illness, identify the pros and cons of using quantitative versus qualitative designs, and consider new methods that combine the best of both approaches.

## Learning Objectives

At the end of this module you will be able to:

- Identify at least two kinds of research designs that have traditionally been used to study the recovery process and interventions
- Discuss at least three of the pros and cons of quantitative and qualitative research vis a vis the concept of recovery
- Describe two of the differences between medical research and social science research carried out in the community
- Explain at least two recent innovations in research designs for community based studies
- Discuss at least two of the potential advantages of new research methodologies and describe any challenges that may be apparent

## Resources

- Lecture Notes
- Required Readings
- Lecture Notes Citations
- Sample Learning Activity
- Sample Evaluation Questions
- Additional Resources

## Required Readings

Anthony, W., Rogers, E. S. & Farkas, M. (2003). Research on evidence-based practices: Future directions in an era of recovery. *Community Mental Health Journal*, 39, 101–114.

Bellack, A. S., Green, M. F., Cook, J. A., Fenton, W., et al. (2007). Assessment of community functioning in people with schizophrenia and other severe mental illnesses: A white paper based on an NIMH-sponsored workshop. *Schizophrenia Bulletin*, 33, 3, 805–822.

Essock, S. M., Drake, R. E., Frank, R. G. & McGuire, T. G. (2003). Randomized controlled trials in evidence-based mental health care: Getting the right answer to the right question. *Schizophrenia Bulletin*, 29, 1, 115–123.

Essock, S. M., Goldman, H. H., Van Tosh, L., Anthony, W. A., et al. (2003) Evidence based practices: Setting the context and responding to concerns. *Psychiatric Clinics of North America*, 26, 919–938.

## Activities

Complete the following activities:

- Read the lecture notes
- Read the required readings
- Engage in a learning activity related to this module
- Evaluate students' understanding of this module.

## Lecture Notes

People with lived experience of serious mental illness are strongly encouraged to be part of the delivery of the curriculum including being active participants in the delivery of the lecture. Refer to the curriculum Instruction module for additional information.

### Introduction

Research documenting that people with serious mental illnesses recover and live satisfying lives in the community began appearing in the literature in the mid 1970s. The early studies were conducted in countries outside the United States and long term outcome data showed that people with serious mental illnesses all over the world had similar recovery rates. In the mid 1980s, psychologist Courtenay Harding published a study of people in Vermont with serious mental illness which documented their recovery and successes in the community. Then, in the mid 1990s, Harding published a compendium of studies which pulled together the evidence from several countries, all of which documented similar rates of recovery from serious mental illness (Harding & Zahniser, 1994). A synthesis of these and more recent studies is provided in the table below:

**Schizophrenia Recovery Research**

Study	Sample Size	Average Length Years	Percent Recovered or Significantly Improved
Bleuler 1972 to 1978 Switzerland	208	23	53-68
Hinterhuber 1973 Austria	157	30 apprx	75
Huber et al 1975 Germany	512	22	57
Chiompi & Muller 1976 Switzerland	289	37	53
Kreditor 1977 Lithuania	115	20+	84
Tsuang et al 1977 USA	200	35	46
Marinow 1986 Bulgaria	280	20	75
Harding et al 1987b 1987c USA	269	32	62, 68
Ogawa et al 1987 Japan	140	22.5	56
Desisto et al 1995a 1995b USA	269	35	49
Marneros et al 1992	148	25	58
Harrison et al 2001 worldwide	1005	15 and 25	43 - 61
Hopper et al Sz only Incidence	502	13 to 17	67
Hopper et al Sz only Prevalence	142	26	63

More recently, several meta-analyses and summaries of newer studies have appeared and all continue to document that individuals with serious mental illnesses can, and do recover from the effects of their illness (Warner, 2010).

Since the early 1970s, and continuing to the present, psychologists, together with consumers, have led efforts to conduct research on recovery outcomes, developed and

tested instruments designed to assess functional skills, and psychologists have developed and tested interventions to assist with the recovery process.

Research designed to identify specific interventions to help people recover from serious mental illness and achieve a satisfying life in the community is relatively new, having taken place primarily in the last fifteen to twenty years. While research to date has not identified a complete picture of what is needed to help people recover, research supports several service models which some experts now consider to be evidence based practices (EBPs) in that they consistently have shown positive results in multiple research studies for the population of people with serious mental illness (Dixon, Dickerson, Bellack, Bennett, et al., 2010). In addition to the EBPs, there are interventions that have not yet achieved the level of evidence that some experts consider necessary to be called an EBP but which have shown considerable promise. These are variously labeled as promising practices or emerging interventions. The specifics of these and other interventions are discussed in greater detail in the modules on Interventions. With that introduction in mind, this module will concentrate on the science that has led to the designation of these categories of service models and highlight the opportunities and challenges of the current state of this science.

## **Research Designs for Recovery Oriented Mental Health Services**

As mentioned, research on how to help people recover from the effects of serious mental illness and achieve a satisfying life in the community is relatively recent. During this time, there have been several studies of community interventions that have adhered to the highest standard of research design, the randomized controlled trial (RCT), and that have produced favorable results. Moreover, these studies have been replicated in subsequent RCTs, indicating that the results can be achieved when fidelity to the researched practice is maintained. This research has changed the landscape of interventions available to people with serious mental illness. Most experts agree that RCTs demonstrating efficacy are necessary before a practice can be considered evidence based and so it is from these studies that the EBPs referred to in the introduction to this module have been identified.

There are many different ways to categorize types of research, such as experimental vs. non-experimental, quantitative vs. qualitative, etc. The first section below details some examples of the types of traditional research methods and designs that are used to advance the knowledge base. As will be seen, none of these approaches, when used separately or sequentially, has the capability to answer the myriad of questions that arise when attempting to discern the best approach to services offered to people with serious mental illnesses. To do that, a combination of approaches, carried out in one single study, offers the best hope. The section following the one below on traditional methods details this relatively new combination approach, known as mixed methods research.

## **Quantitative Studies – Experimental Designs**

As in other scientific fields of study, the RCT is considered the gold standard for research on the recovery process and interventions designed to help people recover. But the use of RCTs in research on recovery and rehabilitation interventions emerged from the RCT standard used to test medical interventions, where only one or very few variables are under study, where the variable(s) can be controlled, and where one outcome is typically desired. In medical research, RCTs are relatively easy to design and carry out. In such studies, extraneous variables are either controlled or are not relevant to the outcome. The interventions in these studies are principally pharmacotherapies and once safety has been determined, the variables to be manipulated are relatively straightforward and easy to manipulate and monitor. Examples of such variables include dosage level, frequency of administration, and duration of the intervention. Finally, in medical research, it is well known that even after a best practice has been identified, new research that emerges often changes the view of that best practice and it is either recalled or superseded by a different practice.

## **Drawbacks to Use of RCTs for Recovery Oriented Interventions**

While noting that RCTs are the research gold standard, there are several drawbacks to using RCTs in community settings where recovery and intervention research is carried out. This is principally due to the large number of variables that must be accounted for and the complexity of the variables and the interactions that occur. Impediments include generalizability to populations or settings different from those of the original research (population characteristics, geographical areas, client characteristics, etc.), cost and length of time required to complete the study, the multitude of variables usually under study in community research and those not under study but that can influence the outcome, and the difficulty of maintaining subjects for long periods of time especially when intervening factors may emerge such as changes in life situation and symptom exacerbation. These are but a few of the difficulties with using RCTs in community research.

If we contrast the relatively straightforward research on a drug treatment or other medical intervention with the highly complex and multi-component characteristics of the psychosocial rehabilitation (PSR) EBPs, dramatic differences become apparent. While significantly advancing our efforts to help people with serious mental illness achieve the goals they have identified for themselves, the current state of research on EBPs and other interventions has many unanswered questions. Like much of social science community research, the EBPs are, for the most part, multi-component interventions that can be difficult to implement with fidelity in non-research environments. Often the EBPs are resource intensive and can require that individuals remain committed to the intervention for long periods of time. It may be that some, but not all, of the components contribute most to the outcomes observed. But, to date, there has been virtually no research designed to tease apart the efficacy or effectiveness of the component parts of the EBPs. Such research could potentially help clinicians know which components are critical to achieve a

given result, making the potential for providing an effective intervention with fewer resources more likely. There has also been little research to identify the components of a given intervention that people with serious mental illness value most, i.e., those that individuals think were most helpful such as a hopeful, valuing environment and an empathic, trusting relationship. Such research could help to increase the likelihood that people with serious mental illness would accept the intervention, or specific components of the intervention, in a non-research environment, i.e., a community mental health setting.

Also important is the fact that some of the factors mentioned by people with serious mental illness as critically important for recovery are difficult if not impossible to measure quantitatively as is necessary in an RCT, sometimes due to ethical reasons (Anthony, Rogers & Farkas, 2003; Drake, Goldman, Leff, Lehman, et al., 2001; Hogan, 2010; Rogers, Farkas & Anthony, 2004). Examples include a person's sense of hope that recovery is possible, the relationship between the person with the illness and his or her mental health practitioner, and the person's perceptions about his or her quality of life. Clearly it would not be ethical to encourage hope of recovery in one group but discourage that sense of hope in another group. Nor would it be ethical to work toward establishing a trusting relationship in one group of people and work against that kind of relationship in another group of people. So, while it is always desirable to conduct research using the highest standard, i.e., an RCT, doing so in certain research endeavors is considerably more difficult and may not be practical or ethical.

### **Quantitative Studies – Quasi-experimental Designs**

Given that it may not always be feasible to use an RCT design for research on recovery oriented interventions, the next most rigorous design within the category of quantitative research is the quasi-experimental design. Unlike in an RCT, random assignment to groups (e.g., experimental and control groups) does not occur in a quasi-experimental design. One common example of the quasi-experimental study is the nonequivalent groups design, in which two (or more) naturally occurring groups that are thought to be similar are selected for investigation. One group receives a treatment or participates in an intervention; the other does not. Then pre- and post-test scores from groups are compared to see if the intervention group showed a differential effect than the non-intervention group. Although causality cannot be ascribed to one variable or another in a quasi-experimental study, these are the types of studies often undertaken in community settings because of the many variables that often cannot be completely controlled. Despite not being able to make definitive causal inferences, these studies have the advantage of providing valuable and often necessary information that could not be obtained through purely experimental methods. For applied research questions such as those related to recovery from serious mental illness, quasi experimental studies offer the possibility of obtaining information that may not be obtained from a purely experimental study.



## **Non-experimental Quantitative Studies – Observational Research, Survey Research, Program Evaluation and Other Methods**

Non-experimental research, sometimes also called correlational research, describes behavior and looks for relationships between variables. Although causality cannot be ascribed to one variable or another in a correlational study, these studies are also often undertaken in community settings because of the challenges of assigning individuals to groups. Observational research consists of the systematic observation of behavior and while no intervention is provided, can be useful for gathering information about the occurrence of one or more behaviors or patterns of behavior. In an observational study, data are collected and analyzed, and the researcher looks for relationships between the variables of interest. For example, although most often used to look at a condition's prevalence, incidence, correlation with other variables, or prognosis (Mann, 2003), observational methods such as case controlled studies can be used to generate hypotheses that can be experimentally tested after initial information is obtained. If subjects can be contacted over time, longitudinal case controlled studies can be especially useful. Despite not being able to make definitive causal inferences, these studies have the advantage of providing valuable and often necessary information that could not be obtained through purely experimental methods. One grading scheme that has been developed to assess how rigorous and meaningful a non-experimental research finding may be is the Standards for Rating Program Evaluation, Policy or Survey Research, Pre-Post and Correlational Human Subjects Studies, which is one component of the Quality of Disability Research Instruments (QDRI) scale (Rogers, Anthony, Kash & Farkas, 2008). The scale provides a mechanism for assessing a variety of factors that can impact on the quality of non-experimental research.

### **Qualitative Studies**

All of the above methods have limitations that impact their usability and applicability. RCTs frequently cannot be applied to real world settings and quasi experimental and non-experimental methods often encounter selection bias and other complexities that confound the study and its results. Having discussed the most frequently used quantitative research designs, it is equally important to discuss qualitative research methods because of the value they add to quantitative data.

Qualitative research refers to a diverse method of inquiry where data consist of something other than numbers, most commonly text. Examples of qualitative methodology include focus groups, interviews, or analysis of written narrative documents. Qualitative studies are often considered hypothesis-generating. This means that researchers might do a qualitative study when there is no obvious hypothesis, or when the area of investigation is new. By learning more about the area of interest, the researcher can begin to develop hypotheses that can then be studied using quantitative methods. Some of the results from qualitative studies have been the driving force behind development of the EBPs. These include the importance of several factors such as the person's relationship with mental health practitioners, setting goals that are important to the individual, development of skills to

assist the person attain his or her desired goals, and helping the individual to develop resources needed for support and goal accomplishment (Farkas & Anthony, 2010; Rogers, Farkas & Anthony, 2004). Qualitative studies can be a good place to start when attempting to understand a complicated construct like recovery. By asking people about their experience of recovery and looking for themes, researchers can begin to understand the construct before deciding on study designs that allow for quantitative study. Qualitative data can also provide information that is highly descriptive and allows the researcher to understand why something is the way it is, i.e., qualitative data add contextual detail.

## **What Does it All Mean and What is the Best Way Forward?**

From the discussion above, it should be clear that there are advantages and disadvantages to both categories of research. The debate about which kind of research design to use is one that has taken place for the past several years, continues to this day, and will likely continue for some time to come. Recently however, suggestions have emerged about how to move forward in carrying out social science research especially in the community (Creswell, Klassen, Plano Clark & Smith, 2011). These suggestions seem particularly appropriate for our efforts to learn which interventions work best for people with serious mental illnesses.

In any research endeavor, it is important to use the strongest research design that is also best suited to answer the questions of interest. The researcher, and ultimately, the user or person evaluating the usefulness of that research, should be able to appraise the research findings based on the characteristics of the question(s) that were under study. In order to obtain the best answer(s) to complex questions such as those posed in recovery and rehabilitation intervention research, it may be necessary to use more than one approach – this is in fact what many experts in the field are calling for (Anthony, Rogers & Farkas, 2003; Essock, Goldman, Van Tosh, Anthony, et al., 2003; Farkas & Anthony, 2010). This has been stated succinctly by the NIH Office of Behavioral and Social Sciences Research:

Furthermore, while randomized clinical trials allow for a causative interpretation of what studied factors bring about change, it is through qualitative, ethnographic, and process analyses that one can focus specifically on what the participant perceives and experiences as the change process. These essential ingredients in the change process may not be evident unless subjective measures and qualitative approaches are included in our research repertoire. The point is not whether qualitative or quantitative measures are better; rather it is that they are complementary and not duplicative (Office of Behavioral and Social Sciences Research, 2001).

## **Using Multiple Approaches to Find the Best Answers: Mixed Methods Research**

Applying research outcomes to benefit practice is the reason for conducting the research in the first place. While research following the highest scientific standards is always the goal, the results of research studies must be applicable to the intended beneficiaries, in this case, people with serious mental illnesses. In some cases, neither purely experimental research

nor purely non-experimental research has satisfied the criteria (Tanenbaum, 2005). Finding the right mix of science, practicality, usability, generalizability, etc. can be difficult, but may not be impossible. Enter the relatively new world of mixed methods research.

In response to the debate about the best way to obtain evidence on what works in social service, health, and community research, some researchers have suggested and begun using more than one approach in studies where there are multidimensional variables, potentially complex interactions, and where the research conditions cannot be tightly controlled. This new approach has been termed mixed methods research (Creswell & Plano Clark, 2011; Tashakkori & Teddlie, 2003; Teddlie & Tashakkori, 2009).

In mixed methods research, quantitative and qualitative data collection and analysis are combined **in the same study, not in sequential processes, but as part of one overall design**. The central premise of mixed methods research is that using quantitative and qualitative approaches at the same time provides a stronger design and a better way to view the research question and the study results than either approach alone. This is the distinctive feature of mixed methods research and when carried out in this way, studies are said to have used a mixed method design. While researchers have collected and analyzed both kinds of data for many years, putting both together in the same research design has not typically been the case, although use of this approach has been increasing in recent years (Palinkas, Horwitz, Chamberlain, Hurlburt & Landsverk, 2011). In fact, the Office of Behavioral and Social Sciences Research at NIH recently sponsored development of a guidance document aimed at helping potential grantees understand and use mixed methods research. The authors of the document defined mixed methods research as follows:

...a research approach or methodology:

focusing on research questions that call for real-life contextual understandings, multi-level perspectives, and cultural influences;

employing rigorous quantitative research assessing magnitude and frequency of constructs and rigorous qualitative research exploring the meaning and understanding of constructs;

utilizing multiple methods (e.g., intervention trials and in-depth interviews);

intentionally integrating or combining these methods to draw on the strengths of each; and

framing the investigation within philosophical and theoretical positions (Creswell, Klassen, Plano Clark & Smith, 2011).

Since a narrow view of any question or concept can lead to misleading or incorrect conclusions, broadening the way research questions are looked at would seem to enhance the possibilities for gaining the most from studies of recovery and PSR services. Proponents of the mixed method approach believe that such research broadens the array of questions

that can be asked and potentially answered and offers the possibility to do so all within the same study. The approach also may be able to provide stronger inferences, offer the potential to present a wider range of views based on the results of such studies, and allows investigators the possibility to answer both exploratory and confirmatory questions in the same study thereby permitting verification and generation of theory in the same study (Kemper, Stringfield & Teddlie, 2003). Although not routinely used by those studying recovery and rehabilitation interventions, combining quantitative and qualitative designs may be the approach of choice for studying the variables of interest in the recovery paradigm and PSR interventions. Due to the potential to more quickly answer many of the remaining questions about what works best for whom and under which conditions, it is hoped that use of mixed methods designs will increase in frequency.

## Challenges

Research on the recovery process and interventions in community settings is very complex and typically has a large number of variables to be controlled. Identifying the best method to conduct such research in order to find answers to the questions under study is the overarching challenge.

Although several challenges could be identified, two of the most obvious ones will be discussed here. These are, first, what should we be studying, and secondly, how should we be studying it? Within each of these, there are additional questions that are equally important and add to the complexity of these two primary questions.

Regarding the first, the interventions that have been designated as EBPs and promising practices emerged from two sources, a) the concrete targets identified by people with serious mental illness as necessary to achieve a satisfying life in the community, i.e., good relationships with family and friends, satisfying work, an ability to manage symptoms, etc., and b) the somewhat more intrinsic characteristics and helping processes identified by people with serious mental illness as crucial for recovery such as a sense of hope, respect, self-direction, etc. As targets of research, both of these have been equally applauded and criticized for one reason or another.

While no one takes a strictly either/or position, many psychologists can be found on one side or the other in the debate about the value of studying each of these. Those in favor of studying the interventions believe that the best way help people recover is to assist them with the skills necessary for successful community living. Those in favor of studying the characteristics of recovery believe that no intervention will be helpful if these underlying values and supports are not present. Logic would dictate that both are correct.

Embedded within this first challenge is yet another question that is related to intervention research. This has to do with teasing apart the components of those interventions found to be effective to determine which contribute to the success of the overall intervention, and which if any, are not crucial to achieve the desired outcome.

The second major challenge is very much linked to the first. It concerns the best way to study the variables of choice, i.e., interventions or underlying values and characteristics. Some believe that quantitative studies have the most value because if done properly, causality can be ascribed based on the outcome. Others believe that qualitative studies have the most value because of the richness of the information that can be gathered and the ability to link this information directly to individuals' beliefs about the variables under study. To date, research has tended to concentrate on one or the other, with most intervention research carried out using quantitative methods and most studies looking at characteristics and values of the recovery paradigm using qualitative methods. Often when one method is the primary approach, additional data will be collected using the other method, but this has not been truly satisfying because the data and analyses are not fully integrated, leaving many unanswered questions. The recent development of mixed methods approaches holds promise for resolving some of these dilemmas, but the techniques are not well known and are not used as frequently as might be desired. Most psychologists are trained in the methods associated with quantitative research although there is increasing interest among psychologists in studying quantitative research techniques. Fewer psychologists yet are trained in mixed methods approaches; this approach may be the most valuable however.

While all of the issues will likely not be solved in the very near future, our knowledge about how best to assist people with serious mental illness will be advanced by a broadened and more comprehensive view of the kinds of questions that should be asked and the research methods best suited to find answers to those questions. Training psychologists to embrace all possible research methodologies may be a significant challenge in and of itself. Training psychologists in the skills needed to carry out mixed methods research may be the best answer and offer the best of both worlds.

## Summary

While recovery oriented research is relatively recent, significant gains have been made in our knowledge about the interventions and processes that are available to help people with serious mental illness achieve the kind of life they choose. Examples include the EBPs, promising or emerging practices, and the components of the recovery paradigm. This knowledge has been gained through quantitative and qualitative research and despite the continuing debate about which has more value, neither approach has contributed more than the other – each approach has advantages and limitations.

Neither of these research approaches is singularly capable of producing the kinds of results that are needed to truly advance the field and enable widespread use of the knowledge gained. A relatively new methodology called mixed methods research is increasingly being promoted as one solution to the problems encountered in complex community based research. This methodology combines both quantitative methods and qualitative methods within one study design and proponents argue that this approach substantially strengthens

the inferences that can be made from the results of a single study. While the final answer is not likely to appear in the very near future, use of this new design approach may hold promise for adding more quickly and more thoroughly to our knowledge of recovery and rehabilitation, ultimately enhancing psychologists' ability to assist people in their recovery from serious mental illness.

## Sample Learning Activity

For this activity, a consumer participant is asked to list six things that he or she considers to be most important for his or her recovery. The items can be such things as feeling hopeful, having good social skills, having meaningful work, being able to direct one's own recovery services, etc. There are no restrictions on the items that can be listed. The items listed should be written on two large sheets of paper that all can see. The consumer participant should very briefly describe the items that he or she listed. This portion of the learning activity should take no more than fifteen minutes – in the interest of time, the consumer participant could be asked to come prepared with the list.

Once the list is completed, all participants are split into two groups, and the consumer participant will move back and forth between each group. Each group is to design a research study that is best able to determine the impact of all the listed items for people with serious mental illnesses. The limitations of each of the designs should be highlighted and solutions to those limitations offered.

## Sample Evaluation Questions

### Question

### Correct Answer

1. The primary advantage of using an RCT in community based research is:
  - a) the control over complex variables that can be achieved
  - b) causality can be determined
  - c) generalizability is assured
  - d) all of the above
  - e) none of the above

b) is correct
2. Qualitative studies have been praised for their ability to:
  - a) provide contextual information
  - b) allow the researcher to understand why a finding has emerged
  - c) identify emerging areas of study
  - d) all of the above
  - e) none of the above

d) is correct
3. Research on the evidence based practices has advanced the knowledge base because:
  - a) it has provided insight into the components of recovery and the characteristics people with serious mental illness have identified including the importance of hope, self direction, respect and empowerment
  - b) the relative value of each of the components within the practices has been identified
  - c) the importance of a trusting relationship with the practitioner has been firmly established
  - d) all of the above
  - e) none of the above

e) is correct
4. The biggest challenge to research on recovery and community rehabilitation interventions is:
  - a) researchers' inability to resolve the debate about quantitative vs. qualitative approaches
  - b) the lack of a research method that can definitively answer all questions
  - c) researchers' and consumers' differing views of the topics that should frame the research
  - d) all of the above
  - e) none of the above

e) is correct
5. In mixed methods research designs:



- a) quantitative and qualitative design, methods, data collection and analyses are combined under one design
  - b) complex constructs and variables can be investigated at the same time that contextual constructs and variables are investigated
  - c) a broader array of research questions can be asked
  - d) the researcher has the possibility to both verify and generate theory in the same study
  - e) all of the above
- e) is correct

## Lecture Notes Citations

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## **Additional Resources**

American Psychological Association Recovery to Practice Initiative.

<http://www.apa.org/pi/rtp>

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## Citing the Curriculum

Citation for this Module:

American Psychological Association & Jansen, M. A. (2014). Scientific Foundations. *Reframing Psychology for the Emerging Health Care Environment: Recovery Curriculum for People with Serious Mental Illnesses and Behavioral Health Disorders*. Washington, DC: American Psychological Association.

Citation for the full Curriculum:

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