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

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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


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, Olsson, 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**

<table>
<thead>
<tr>
<th>Barriers to mental health care for refugee youth</th>
<th>Strategies to address barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Distrust of authority/Power</td>
<td>Community engagement</td>
</tr>
<tr>
<td>Stigma of mental health services</td>
<td>Embedding services in service system</td>
</tr>
<tr>
<td>Linguistic and cultural barriers</td>
<td>Partnership of providers and cultural experts</td>
</tr>
<tr>
<td>Primacy of resettlement stressors</td>
<td>Integration of services</td>
</tr>
</tbody>
</table>

*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:

<table>
<thead>
<tr>
<th>Hinders Recovery – Programs &amp; Services</th>
<th>Helps Recovery- Programs &amp; Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coercion &amp; Forced Treatment</td>
<td>Freedom of Whether &amp; How to Participate in Services &amp; Meds/ Self-Management of Medications</td>
</tr>
<tr>
<td>Treatment/Medication used as a means of Social Control</td>
<td>Inpatient Services as Last Resort but Available/ Small Scale/ Alternatives to Hospitalization/ Self-Directed Inpatient Care/ Advanced Directives Respected</td>
</tr>
<tr>
<td>Debilitating Effects &amp; Experiences of Long-Term Hospitalization</td>
<td>Quality Clinical Care/Consumer-Doctor Partnership/Up-to-date Treatment Knowledge /Clean &amp; Modern Program Environment</td>
</tr>
<tr>
<td>Substandard Services/ Poor Quality Assurance</td>
<td>No Waits/ Flexible</td>
</tr>
<tr>
<td>Limited Access to Services &amp; Supports/ Timeliness, Time limits</td>
<td>Coordinated Services Across Problems, Settings, &amp; Systems/Effective Case Managers with Low Caseloads &amp; High Pay/ Disengagement or Reductions in Services Based on Consumer’s Self-Defined Need</td>
</tr>
<tr>
<td>Fragmentation of Services, Eligibility Restrictions</td>
<td>Tailored to Individual/ Wide Range of Choices as to Who Provides, What is Provided &amp; Where Provided</td>
</tr>
<tr>
<td>Lack of Individualization</td>
<td>Peer Support Services/ Therapy &amp; Counseling/Atypical Meds/Family Services/Employment Support &amp; Career Development/Respite Care/Integrated Dual Diagnosis Services/Jail Diversion and Community Reintegration Services</td>
</tr>
<tr>
<td>Lack of Needed Range of Services, Treatments and Options</td>
<td>Patient Education/ Illness Education/Information on Meds, Effective Treatments &amp; Services &amp; How to Secure, Rights/ Family Education/Public Awareness Education (anti-stigma &amp; pro-recovery)</td>
</tr>
<tr>
<td>Lack of Education for Consumers, Family Members and Community (e.g., illness, self-care, services, etc.)</td>
<td>System Navigators/ Extensive Out-reach &amp; Support (multiple languages, 24-7, minority-focused)/ Homeless Outreach/ Safety Net Services</td>
</tr>
<tr>
<td>Inadequate Continuity of Care</td>
<td>Access to Records/ Can Change Inaccurate Information</td>
</tr>
<tr>
<td></td>
<td>Early Intervention &amp; Public Screenings/ Outreach to Churches, Schools, Community</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Question</th>
<th>True</th>
<th>False</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The goal of self-direction is more important than a person’s cultural preferences</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>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</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>3. In order to help people engage in services, professionals must be empathic and experts in various forms of psychotherapy</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>4. Assertive outreach includes ensuring the persons to be served have their basic needs met, including those for safety, shelter, and suitable activities</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>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</td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>
Lecture Notes Citations


Additional Resources


**Citing the Curriculum**

Citation for this Module:

Citation for the full Curriculum:

For additional information, contact:
Recovery to Practice initiative at the American Psychological Association, [www.apa.org/pi/rtp](http://www.apa.org/pi/rtp)
or
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