THE TEMPLE UNIVERSITY COLLABORATIVE ON
COMMUNITY INCLUSION
of Individuals with Psychiatric Disabilities

SERVING PEOPLE WITH PSYCHIATRIC DISABILITIES IN CENTERS FOR INDEPENDENT LIVING

A FACT SHEET

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Introduction

Centers for Independent Living across the country are increasingly aware of the need to develop more effective ways of working with CIL consumers who have psychiatric disabilities, or who have both physical/sensory and psychiatric disabilities. This 'Fact Sheet' responds to the need for very basic information, and was developed in cooperation with several leaders in the CIL movement and CIL staff. More information on each topic discussed here can be found by looking at the websites suggested.

There are many similarities in the values of the independent living movement and the recovery/community inclusion emphasis of mental health providers, both driven by strong consumer advocacy movements over the last twenty years. Both value the voices of consumers, both believe in the dignity of risk, and both emphasize consumer control over treatment decisions.

There are rare situations when people experience the kind of psychiatric crisis that leaves them a danger to themselves or others and may require a stronger intervention to insure that someone's life is not at imminent risk. Even in these unusual circumstances, however, mental health providers should be aware of the consumer's treatment preferences, and then seek to stabilize the individual so that decision making is returned to the consumer as quickly as possible.

We believe that you may want to use this Fact Sheet as a way to start a discussion within your CIL and/or with your local mental health providers about the values you share when working with consumers with psychiatric disabilities.

1. What is mental illness?

Mental illnesses are best described as a variety of behaviors and/or ways of thinking that can disrupt an individual's ability to lead a happy and productive life. The symptoms of mental illness vary widely, but include such things as depression and anxiety, paranoia and fearfulness, confused thinking and the kinds of delusions that people often describe as 'hearing things' and 'seeing things' – symptoms that are difficult for individuals to deal with when they are severe and persistent, and may lead to behaviors which are very challenging for CIL workers. While the exact cause is unknown, most experts believe that a combination of genetics, environmental stressors and traumatic events lead to the development of mental illnesses, and that this combination varies from person to person.

For more information on the Definition of Mental Illness and Some Common Diagnoses, please see: Center for Psychiatric Rehabilitation: What is Psychiatric Disability? http://www.bu.edu/cpr/reasaccom/whatis-psych.html

2. What are the diagnoses associated with mental illnesses?

Mental health professionals use a wide range of diagnoses to describe certain prominent symptoms, or groups of symptoms, that are impacting on the lives of the people they serve, and most public and private mental health funding systems require a psychiatric diagnosis in order for mental health service providers to be reimbursed. CIL workers may want to know more about both the general diagnostic categories as well as the particular diagnoses used in the mental health system. Examples of some general diagnostic categories are:

affective disorders—also known as mood disorders, these are characterized by dramatic changes or extremes in affect and emotion. Depression and bipolar disorder are two types of affective disorders

schizophrenia—a type of mental illness which tends to have all or some of the following symptoms: hallucinations, delusions, blunted or flat emotions, withdrawal from reality and disorganized thinking.

anxiety disorders—these are characterized by extreme fear associated with certain objects or situations.

personality disorders—these tend to be long-lasting, deep-seated patterns of behavior and thinking which often differ from the cultural norm and cause problems in social functioning.

substance abuse—these disorders involve the overuse and dependence on substances like alcohol and illegal drugs.

For more information on the types of psychiatric diagnoses, please see:
WebMD: http://www.webmd.com/mental-health/mental-health-types-illness or
NAMI:http://www.nami.org/Template.cfm?Section=By_Illness

3. What types of help are available to people with mental illnesses?

People with mental illnesses often use a variety of mental health services, whether in public or private mental health systems. These include:

therapy – in either individual or group therapy, people are encouraged to talk about their problems and seek new ways of thinking or behaving

medication – most people with serious mental illnesses also take medications, which can be very effective in moderating symptoms and stabilizing their lives

rehabilitation - a wide range of programs offer those with mental illnesses help with housing, employment, friendships, education, finances, healthcare, etc.

For information on different types of psychotherapy and what one can expect when they start psychotherapy, please see:
http://www.mayoclinic.com/health/psychotherapy/MY00186/DSECTION=what-you-can-expect

For more information on medications, how they work and the kinds of medications prescribed for different conditions, please see the:
National Institute of Mental Health's medication publication
http://www.nimh.nih.gov/health/publications/mental-health-medications/complete-index.shtml

For more information about what psychiatric rehabilitation is, and what psychiatric rehabilitation practitioners do, please see:
http://www.uspra.org

4. Do people with mental illnesses get better?

Most people with mental illnesses do get better: on the one hand, therapy, medications, and rehabilitation help many people to return to good mental health and go on with their lives; on the other hand, research shows that the majority of people who continue to have symptoms are able, with services and supports, to lessen those symptoms and/or to learn how to live a satisfying and fulfilling life despite their psychiatric disability and its symptoms. A mental illness is

no longer considered a chronic condition, or one where there is considered no hope for improvement.

For personal stories of recovery by people with psychiatric disabilities, please see:
http://www.nami.org/Content/NavigationMenu/Find_Support/Consumer_Support/Preface_to_Recovery_Stories.htm

and to purchase a compilation of stories of recovery, please see:
http://www.bu.edu/cpr/products/books/titles/voices.html

5. Where can people with psychiatric disabilities turn for help?

CIL staff can play a key role in helping people with psychiatric disabilities find assistance. For people with private (e.g., employer) insurance, their insurers can refer them to psychiatrists and/or counselors who can be of help. For people with more limited incomes, the public mental health system provides a wide array of therapy, medication, and rehabilitation services – and the best way to start is to contact your state or local mental health authority, or a local mental health association, for referral information.

For more information about how to access mental health services, contact your county or state Office of Behavioral Health (which may have another but similar name) or your local Mental Health Association. Local MHAs, can be found through Mental Health America's national website: http://www.nmha.org/. On the NMHA homepage is a Find an Affiliate map where CIL workers can identify their local MHA by zip code.

6. What services/supports are available from public mental health agencies to assist people in living and integrating into the community?

Most public mental health services offer a wide array of help, including diagnosis, treatment, and emergency services, but also help with housing, employment, socialization, connection to mental health consumer groups, and more. CIL staff will want to find out from each consumer who may benefit from mental health care if he or she is already in care, and, if not, ask if the consumer would like a referral. Public mental health systems provide:

inpatient care – when someone is a danger to themselves or others, either a short-term inpatient unit in a community hospital or a brief state psychiatric hospital stay may be necessary

outpatient care -- an intensive program in a community setting in which the consumer will receive individual and group therapy, and may also have access to rehabilitation programs of various types

partial hospitalization services/day treatment programs – available for consumers who need less intensive services and are ready to focus on community adjustment issues

case management services – which help consumers coordinate their mental health treatments, rehabilitation services, and practical aspects of life

For more information about the case management profession, please see:
http://www.yournacm.com/welcome.html

7. What other services/supports are available to assist people in living and integrating into the community?

The following types of services can be offered by public mental health agencies, by private mental health agencies and by agencies run by consumers directly:

rehabilitation services – offering help with finding a place to live, finding a job training program or a job placement, developing social skills, etc.

consumer-run services – many state and county mental health authorities now support programs run by and for consumers themselves

supported housing programs -- these programs offer consumers affordable, permanent housing in the community, often linked to treatment, employment, addictions, and health care supports

clubhouses – these are local support and social centers for consumers that are run by staff and clubhouse members together and offering social, vocational, residential, and other supports

For information about the National Association of Psychiatric Rehabilitation Practitioners, please see United States Psychiatric Rehabilitation Association:
www.uspra.org

For more information about Consumer-Operated Services, sample programs in the United States, and the philosophy behind Consumer-Operated Services, please see:
http://www.ilru.org/html/publications/newsletters/Briefs/Vol2Iss2.pdf

For more information on supported housing programs, please see:

http://www.nami.org/MSTemplate.cfm?Section=21&Site=NAMI_Vermont&Template=/ContentManagement/HTMLDisplay.cfm&ContentID=25738

For more information about the clubhouse movement in the United States, please see the International Center for Clubhouse Development website at: http://www.iccd.org/mission.html

8. What are the best evidence-based practices in the field today?

The federal Substance Abuse and Mental Health Services Administration has identified six 'best practices' that research indicates are especially helpful:

assertive community treatment – a team approach to making sure that people with serious psychiatric disabilities do well living in their communities

illness management and recovery – a systematic way for individuals with psychiatric disabilities to take more responsibility for their own wellness by responding earlier to emerging problems

supported employment – a work-oriented program that moves individuals with psychiatric disabilities back to competitive work as quickly as possible, providing long-term supports to insure job retention

integrated dual diagnosis treatment – linking mental health and substance abuse services for people who struggle with both issues, and linking the services provided by both MH and SA providers

medication management – a way for people with psychiatric disabilities to learn how to manage their psychotropic medications more effectively by learning more about medications, side-effects, and long-term impacts

family psycho-education – informing families of people with psychiatric diagnoses about mental illnesses and both the supports available in mental health systems and the supports family members themselves can offer

For more information on these evidence based practices, please see:
http://ebp.networkofcare.org/index.cfm?pageName=index

For more information on purchasing SAMHSA toolkits on evidence based practices, please see:
http://store.samhsa.gov/facet/Professional+%26+Research+Topics/term/Evidence-Based%20Practices?headerForList=

9. What are the major trends re-shaping mental health care today?

Mental health systems have been in the process of transformation over the past twenty years, and today there is a much greater emphasis on self-determination, recovery, community inclusion and peer support.

self-determination – mental health systems increasingly recognize the importance of consumers making decisions for themselves – about their goals, about the nature and pace of the treatments and rehabilitation services they receive, and about the policies that shape mental health service options – an approach very similar to (and borrowing from) the fundamentals of the CIL approach.

recovery – mental health systems today have left behind the older notion that people with mental illness are 'chronic' or 'cannot be helped' in favor of a more positive approach, believing that almost everyone with a serious mental illness can make real progress in learning to live a satisfying, productive life despite the persistence of symptoms.

community inclusion – mental health systems are increasingly aware that many mental health consumers need to spend less time in mental health agencies and more time drawing upon the everyday resources of their communities – the recreation centers, schools and colleges, churches and synagogues, job training programs, housing services, and social opportunities available to anyone without a psychiatric disability.

peer support – many mental health programs – including peer-run programs – employ 'peer specialists' to offer those with psychiatric disabilities the 'one-to-one' support of someone like themselves – someone who has 'been there' – to encourage and support them. Peer specialists often help consumers develop both a *Wellness Recovery Action Plan* (WRAP) to set recovery-oriented goals and *Psychiatric Advance Directives* (PAD) to ensure that their wishes are followed during times of crisis.

integrating mental health care with primary care - growing awareness that people with serious mental illnesses have a life expectancy that is 20-25 years *shorter* than for those without mental illnesses has led to many new programs emphasizing basic physical health care for those with psychiatric disabilities: despite multiple causes - often the symptoms of mental illnesses and the side effects of medications have detrimental physical effects, for example, weight gain and smoking are common for people with mental illnesses as are high blood pressure, high blood sugar, and high cholesterol - efforts have been made to promote wellness programs such as smoking cessation, weight loss and personal fitness.

For a history of the Consumer/Survivor Movement, please see: SAMHSA—ADS Center:
http://www.promoteacceptance.samhsa.gov/teleconferences/archive/training/teleconference12172009.aspx

To learn more about SAMHSA's National Consensus Statement on Mental Health Recovery:
http://store.samhsa.gov/product/SMA05-4129

For more information on Community Integration, please see:
http://tucollaborative.org/comm_inclusion/community_integ_intro.html

For more information about what WRAP is all about, please see The Copeland Center:
http://copelandcenter.com/what-is-wrap/

For more information about what PADs are, please see the National Resource Center on Psychiatric Advance Directives:
http://www.nrc-pad.org/

For more information about the integration of primary and behavioral health care:
http://www.thenationalcouncil.org/cs/best_practices_programs *and*
http://www.ibhp.org/index.php

10. How do these trends affect CIL personnel, day-to-day?

CIL workers should keep several issues in mind:

language – the mental health field has come a long way from the time when we referred to people as 'schizophrenics' or 'manic-depressives' or just 'the crazies': more respectful language includes the use of people-first approaches ('a person with schizophrenia,' or 'an individual hearing voices,' etc.) that places the emphasis on the fact that the individual in question is more than their illness and is first of all a person;

privacy – people with psychiatric disabilities – like anyone else with a medical condition – are entitled to

privacy with regard to their psychiatric history and current use of resources: HIPPA regulations apply, of course, but it is also important to recognize the dignity of individuals and insure that we are respectful enough to protect their privacy.

For more on person centered language guidelines from USPRA, please see:
http://www.bu.edu/cpr/prj/langguidelines.pdf

For more about appropriate terms for clinical conditions, please see Substance Abuse and Mental Health Services Administration—Guidance on Transformational Language:
http://www.promoteacceptance.samhsa.gov/publications/TransformationalLanguage.aspx

For more information on why person centered language is important , please see Advocacy Unlimited: People First Language: Dignity, Not Semantics:
http://www.mindlink.org/people_first_language.html

11. How can CIL staff respond to the needs of these consumers?

Learning more about mental illnesses is an important first step, and helping people to access the private or public mental health services available to them – if they have not already done so – can be critical. You may want to jot down (in the sections at the end of this fact sheet) the information you may need to contact someone within the mental health system for help with consumers who are having a psychiatric crises, or need case management services, or help with housing or employment issues. However, make sure you ask consumers first for permission to be in touch, on their behalf, with local mental health care providers.

It may be that on occasion, a consumer that you are working with will become agitated or upset. The first thing you should do is assess whether this feeling is reasonable on the part of the consumer. Perhaps you have informed the consumer that he is losing his housing or that she is not eligible for a service that she may need. The best way to respond to consumers with psychiatric disabilities is to respond the same way that you would to any other consumer—treat that person with respect and dignity, be patient, listen to the consumer, look for solutions to the problems presented, and acknowledge the legitimacy of that person's feelings. Remember that a consumer becoming upset or agitated does not usually signal a psychiatric crisis.

If however, a consumer with a psychiatric disability becomes agitated or upset and you feel that the upset is tied to psychiatric symptoms like delusions or hallucinations, then it may be wise to seek assistance. Help that consumer to contact his treatment providers and stay with him until he is able to obtain clinical services.

For additional information on finding your local mental health association, please see the map on the homepage of Mental Health America (has mental health crisis information): www.nmha.org

For additional, more practical information on how to work with a consumer who is agitated, please see: http://www.trivia-library.com/a/handling-and-treating-psychiatric-emergencies-part-1.htm

For additional, broader, clinical information on how to work with a consumer who is agitated, please see: http://www.ispub.com/ostia/index.php?xmlFilePath=journals/ijem/vol4n1/psycho.xml

12. How can CIL staff handle psychiatric emergencies?

Handling a dangerous psychiatric crisis, which is rare, may be particularly challenging for CIL workers, who strongly believe that the consumer should always direct his or her own treatment and care.

use psychiatric advanced directives-- if a consumer has talked to his or her provider ahead of time about his or her treatment preferences in the event of an emergency, the consumer can continue to direct his treatment even if he is not well. Increasingly, consumers and providers rely on completion of a Psychiatric Advanced Directive, which gives consumers, when they are well and able to make better judgments, opportunities to make decisions about the kind of care they would like when they are in the midst of a psychiatric crisis.

handling psychiatric crises -- in the rare case of a psychiatric emergency where consumers have not indicated their treatment preferences, and where consumers may be an immediate danger to themselves or others, involuntary treatment may be needed in order to keep that person and/or others safe and alive. While imposing treatment runs counter to both the CIL philosophy as well as to most psychiatric treatment and rehabilitation providers' philosophy, it may be necessary nonetheless. In the event of a crisis like this– when you strongly believe someone is imminently a danger to themselves or to others – you will want to call 911 or a local mental health emergency unit for help.

If the consumer you are working with is saying that they are thinking about suicide, please have them call the number listed at National Suicide Prevention Lifeline: http://www.suicidepreventionlifeline.org/

Your List of Local Mental Health Resources

Local Mental Health Association (can be found at www.nmha.org)

Contact Person and Title:

Address:

Phone: E-mail: Website:

Notes:

County or City Office of Mental Health

Contact Person and Title:

Address:

Phone: E-mail: Website:

Notes:

Emergency Contacts ((Suicide Crisis Hotlines and Adult Crisis Response Centers)

Name of Center:

Address:

Phone: E-mail: Website:

Notes:

Other Key Contacts

Name/Agency:

Contact person:

Services/Supports:

Phone: E-mail: Website:

Name/Agency:

Contact person:

Services/Supports:

Phone: E-mail: Website:

Name/Agency:

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