

*The University of Illinois at Chicago  
National Research and Training Center's*

*National Self-Determination and  
Psychiatric Disability  
Invitational Conference:*

*Conference Papers*



*"We Make the Road by Traveling on It"*

*Edited by Jessica A. Jonikas, M.A. & Judith A. Cook, Ph.D.  
Chicago, IL: University of Illinois at Chicago*

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The conference theme, "We Make the Road by Traveling on It," was adapted from John O'Brien's "Quotable Quotes, *Topical Shorts, Special Edition: Self-Determination*, Columbus, OH: Irene M. Ward & Associates, 1997.

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## Introduction

On October 2-3, 2003, the University of Illinois at Chicago, National Research and Training Center on Psychiatric Disability sponsored, "The National Self-Determination and Psychiatric Disability Invitational Conference: We Make the Road by Traveling on It." This conference was co-planned with a workgroup comprised primarily of individuals with personal experience in the mental health system. It brought together 50 national experts in a variety of areas related to self-determination, recovery, mental health services, peer support, social change, and political action. The working agenda addressed helping individuals with psychiatric disabilities take charge of their own lives; helping systems change to support this approach to services and policies; and helping communities accept the importance of self-determination for people with mental health and emotional difficulties.

The conference was divided into three tracks: 1) Individual Self-Determination and Recovery; 2) Self-Determination in Mental Health and Other Service Systems; and 3) Societal/Collective Self-Determination. A series of working sessions was held within each track. During these sessions, conference participants discussed issues relevant to what helps and what hinders self-determination for people with psychiatric disabilities. Issues of diversity, gender, age, cross-disability needs/strengths, and the importance of technology were emphasized in each working session.

This monograph is a compilation of the briefing papers presented at the conference. The papers were designed to summarize current knowledge about self-determination at the three track levels, and to suggest action steps for the future.

Specifically, the first conference track papers highlight the authors' personal experiences on the road to self-determination. In their paper, Rogers and Rogers present personal and professional obstacles and facilitators to self-determination for people with psychiatric disabilities. Major obstacles outlined include internal stigma, fear, lack of coping skills, trauma (including forced treatment), not knowing one's rights, hopelessness, and systemic stigma/discrimination. Major facilitators outlined include hope, spirituality, peer support, education, self-advocacy, meaningful employment, and involvement in advocacy work. In her paper, Triano shares a transformative experience in which she learned to overcome internalized shame by understanding, accepting, and taking pride in her identity as a young disabled woman. She also puts forth the importance of knowing one's own history and culture as a disabled person, and how self-love facilitates self-determination. Next, Dansky outlines the ways in which information and communication technologies can facilitate personal self-direction, and provides a number of web-based resources. At the same time, he argues that there are real and perceived challenges and barriers to technology

utilization among people with mental health difficulties that need to be addressed. Finally for this track, Copeland shares her personal recovery story of connecting with other people who shared similar life experiences to document how they took control of their own lives. She outlines a number of common myths and misconceptions about people who are diagnosed, and how these can impede self-determination and self-efficacy. She also describes values and ethics that support self-determination, including such things as mutual respect, dignity, acceptance of diversity, “no-limits” thinking, validation of personal experiences, concentration on strengths, and provision for basic needs (housing, money, food) to support recovery work.

The second conference track papers address the ways in which the current infrastructure and financing of formal service systems are not conducive to self-determination and self-direction for service participants. Onken offers a conceptualization of self-determination and social self-determination within an ecologically based context of recovery, while highlighting how current systems both enhance and hinder client self-direction. Some of the systemic barriers he addresses include bureaucratic program guidelines, limited access to services and supports (including vocational and income support programs), coercive practices, poor quality care, negative messages, and a narrow focus on biology that can discount one’s humanity. Onken concludes with a three-pronged approach to fostering self-determination in formal service systems that embraces choice, interdependence, and vital engagement. In his paper, Nerney also puts forth an agenda for promoting self-determination in service systems for people with psychiatric disabilities. He emphasizes the important parallels between self-determination for people with psychiatric, developmental, and cognitive disabilities. Nerney describes the policy changes necessary within Medicaid and Social Security (as well as Vocational Rehabilitation) that must be made and are possible today under special waivers. These changes could result in easing barriers to employment and self-employment, and make safe housing more available. He ends by analyzing the experiences of one state (MI) that has developed public policy to encourage self-direction in the public mental health system. Leff and his colleagues discuss ways in which quantitative and qualitative research and evaluation can help create systems that promote self-determination for people with psychiatric disabilities. Some of the challenges they outline include the difficulty of operationally defining and measuring self-determination, identifying promising/best practices in this area, and monitoring services and supports for levels of self-determination promoted. They conclude with an agenda for research and evaluation on self-determination systems. Finally for this track, Powers outlines the emergence, components, and structure of person-directed service models for people with a variety of disabilities. These models emphasize an individual’s capacity to assess his/her own needs, to determine how and by whom needs should be met, and to monitor the quality of the services received. She then discusses barriers to the development of person-directed service models for individuals with psychiatric disabilities and next steps for the future.

The third conference track papers focus on societal barriers to self-determination for people with psychiatric disabilities, as well as strategies to address these issues through political and social action. In his paper, Risser outlines specific barriers to self-determination at the societal level, including stigma/discrimination, stereotyping, prevalent myths and misconceptions about mental illness in American society, media and entertainment industry sensationalism, inadequate educational and professional mental health training, and Western medical model biases to name a few. He concludes with recommendations regarding how some of these barriers might be redressed. Next, Wolfe provides the history of the *Contract with Women of the USA* as a model of policy advocacy and highlights several successful initiatives spearheaded by the Center for Women Policy Studies that she directs. She shares many of the strategies the Center uses to advance the rights of girls and women worldwide, and finishes with a series of questions about how to translate the Center's successes into the realm of policy advocacy for self-determination and mental health. In his paper, Oaks inventories some of the major successes of the social change movement headed by people labeled with mental illness over the course of 33 years. He also outlines 10 victories or "wins" that should be celebrated and used to encourage community organizers for self-determination, including: widespread board representation of people with lived experience; the promulgation of user-run centers and groups nationwide; bridge-building with the disability movement; the representation of people recovering from mental health difficulties in United Nations meetings; and the trend for youth with emotional difficulties to become mobilized and organized to speak out. Oaks concludes his paper with a challenge to the consumer/survivor social change movement: will they move forward to face their unique heartache with passionate activism, affirming their role as human beings, interconnected and equal to all others? Finally for this track, Belcher and Muscari discuss how social change is predicated on fostering leadership among people with psychiatric disabilities and reaching more people about self-determination concepts. They outline some common characteristics of leaders, such as ability to inspire, listen, make friends, share credit, avoid discouragement, work hard, and have a sense of humor. Leaders also need to manage power well, handle their workload appropriately, and deal with the pressures of publicly representing the organization. They conclude with a review of successful initiatives led specifically by people with psychiatric disabilities, including the Leadership Academy, Copeland's WRAP model, and the Alternatives Conference.

This unique collection of papers presents a blueprint for mental health self-determination initiatives and models at the individual, service systems, and societal levels. We hope that it will serve to move forward the national conversation about self-determination, particularly as a systems-change mechanism, while providing hope that the promise of self-determination for individuals with mental health and emotional difficulties can be realized.

**UIC NRTC 2003 NATIONAL  
SELF-DETERMINATION &  
PSYCHIATRIC DISABILITY CONFERENCE:**

**CONFERENCE AGENDA**



**The UIC NRTC National Self-Determination and Psychiatric Disability Conference:  
We Make the Road by Traveling On It**

**October 2-3, 2003  
Four Points Sheraton Chicago-O'Hare, Illinois**

**Conference Agenda – Day One**

**Thursday, 10/02/03**

- 9:00-9:15 Welcome, Judith A. Cook, Ph.D.
- 9:15-9:45 Opening Remarks  
Steven J. Tingus, M.S., C.Phil.; Director  
National Institute on Disability and Rehabilitation Research
- 9:45-10:00 Break; Divide into tracks
- 10:00-10:30 Introductions to UIC NRTC facilitators and notetakers; Overview of track purposes & goals; Review ground rules & track questions
- 10:30-11:00 Brief participant introductions
- 11:00-11:45 Paper Presentations

**Track 1:**

11:00-11:30: *Susan Rogers and Joseph Rogers, Mental Health Association of Southeastern Pennsylvania, "Self-Determination for People with Psychiatric Disabilities: Personal Obstacles and Facilitators"*

11:30-11:45: *Genevieve Fitzgibbon, BA, UIC NRTC, "Glass Half Empty/Glass Half Full: An Initial Look at Levels of Self-Determination Reported by Mental Health Consumers Responding to a Web Survey"*

**Track 2:**

11:00-11:30: *Steven J. Onken, Ph.D., Columbia University School of Social Work, "Contextualizing Self-Determination within a Mental Health Recovery Oriented Service and Support System"*

11:30-11:45: *Judith A. Cook, Ph.D., UIC NRTC, "Consumers' Experiences with Self-Determination, the Mental Health System, and Technology: Early Findings of an Internet Survey"*

**Track 3:**

11:00-11:30: *Pat Risser*, “Barriers to Self-Determination for People Who Have Been Identified as Having Mental Illness in Western Society”

11:30-11:45: *Drew Batteiger, BA, UIC NRTC*, “The Potential of the Internet for Promoting Social Change and Activism about Mental Health Issues: Preliminary Results of a Web Survey”

11:45-12:00

Break

12:00-12:30

Paper Presentations

**Track 1:** *Sarah Triano, BA, Co-Founder of the National Disabled Students Union*, “Run for the Stronghold: The Story of One Survivor’s Source of Self-Determination: Self-Acceptance and Love”

**Track 2:** *Thomas Nerney, The Center for Self-Determination*, “The Promise of Self-Determination for Persons with Psychiatric Disabilities”

**Track 3:** *Leslie R. Wolfe, Ph.D., Center for Women Policy Studies*, “The Contract with Women of the USA: A Model of Policy Advocacy for Self-Determination”

12:30-1:30

Lunch (on own)

1:30-3:00

Working session

3:00-3:30

Break

3:30-4:30

Working session

4:30-5:00

Break; Review other tracks’ work

5:00-7:00

Reception

**Conference Agenda – Day Two**

**Friday, 10/03/03**

9:00-9:15

Re-welcome, Judith A. Cook, Ph.D.

9:15-9:45

Opening remarks

Michael F. Hogan, Ph.D., Director, Ohio Department of Mental Health

9:45-10:00	Break; Divide into tracks
10:00-10:30	Paper Presentations
	<b>Track 1:</b> <i>Howard Dansky, Services, Technical Assistance, and Resources for Human Development</i> , “The Role of Information and Communication Technology in Promoting Mental Health Consumers’ Self-Determination”
	<b>Track 2:</b> <i>H. Stephen Leff, Ph.D., The Evaluation Center @ HSRI</i> , “Getting to Systems that Promote Self-Determination through Research and Evaluation”
	<b>Track 3:</b> <i>David Oaks, MindFreedom Support Coalition International</i> , “Mad Movements: Chaordic Paths in Mental Health Activism Toward a Revolution of Empowerment”
10:30-10:45	Break
10:45-11:15	Paper Presentations
	<b>Track 1:</b> <i>Mary Ellen Copeland, Independent Consultant, and Sherry Jenkins Tucker, WV Mental Health Consumers’ Association, CONTAC</i> , “Self-Determination in Mental Health Recovery: Taking Back our Lives”
	<b>Track 2:</b> <i>Laurie Powers, Ph.D., The OHSU Center for Self-Determination</i> , “Person-Directed Services and Support Models”
	<b>Track 3:</b> <i>Larry Belcher, MA, CAGS, CPRP, and Kathy Muscari, WV Mental Health Consumers’ Association, CONTAC</i> , “Fostering Leadership: Collective Self-Determination Among People with Psychiatric Disabilities”
11:15-12:00	Working session
12:00-1:00	Lunch (on own)
1:00-2:00	Finish working sessions
2:00-2:30	Prioritizing exercise (Instructions and Activity)
2:30-3:30	Break Finish individual prioritizing; Review other tracks’ work
3:30-5:00	Working sessions on tools and products Wrap-up and adjourn

**UIC NRTC 2003 NATIONAL  
SELF-DETERMINATION &  
PSYCHIATRIC DISABILITY CONFERENCE:**

**TRACK #1 PAPERS**

**INDIVIDUAL SELF-DETERMINATION &  
RECOVERY**

# Self-Determination for People with Psychiatric Disabilities: Personal Obstacles and Facilitators

***By Joseph A. Rogers, President and CEO, and Susan Rogers, Director of Special Projects, Mental Health Association of Southeastern Pennsylvania***

Although we both have psychiatric disabilities, our respective journeys toward self-determination have been very different. But our stories diverge only in the details; the basics are remarkably similar.

JOSEPH ROGERS:

“In the early '70s, when I was 19 years old and a patient in a Florida state hospital, I had an appointment with the vocational rehabilitation counselor. Standing in front of his desk, I waited while he flipped through my chart. ‘I’ve got nothing much to offer you, since I can see from your chart that you’ll never be able to hold a job,’ he said finally. With these words, he seemed intent on extinguishing any spark of hope I may have desperately held on to that I would one day be the head of my own household. My spirits sank as I contemplated a lifetime of dependency, during which others would have the power to determine my destiny.

“Luckily, upon my release I moved to a typically short-staffed halfway house. To fill in the gaps, the director had the idea of training some of the residents, including me. A lightbulb switched on: I could help others! By doing so, I gained confidence and stature in my own eyes. This was the beginning of my journey toward self-determination, defined within the mental health arena as ‘individuals’ rights to direct their own services, to make the decisions concerning their health and well-being (with help from others of their choice, if desired), to be free from involuntary treatment, and to have meaningful leadership roles in the design, delivery, and evaluation of services and supports’ ([www.psych.uic.edu/UICNRTC/self-determination.htm](http://www.psych.uic.edu/UICNRTC/self-determination.htm)).”

SUSAN ROGERS

“The first of my two hospitalizations was in 1975. My family, fearing (with cause) that I was suicidal, brought a psychiatric outreach team from the local hospital to my apartment on the Upper West Side of Manhattan. After a brief conversation, I was told that I could either enter the hospital “voluntarily” or “involuntarily” — no third option. Offered this so-called choice, I agreed to go “voluntarily,” and was immediately taken to the locked psychiatric ward of the nearby general hospital.

“That I had ‘agreed’ to be locked up against my will was irrelevant, since I had been given no true alternative; and hearing the key turn in the lock while I was on the wrong side of the door filled me with dread. My prospects had seemed bleak before; now, they seemed desperate.

“But things took a turn for the better when I met my roommates: a medical student, a singer, and a Latin teacher. The fact that these three women had lives outside of their current circumstances gave me hope, and the camaraderie we shared was healing. I thought, maybe there is life after psychiatric hospitalization. Although other events during my three-week stay — such as being force-drugged — were less felicitous, I managed to hold on to some degree of optimism.

“As I had not foreseen, a year later, at an even lower ebb, I checked myself back into the hospital. This time, I was in such despair that I could barely speak. But again the luck of the draw was with me: the psychologist who was assigned to my “case” was warm and human, and, at my request, she “reached across” to hold my hand, despite the fact that mental health professionals are discouraged from making that kind of gesture. At my discharge three weeks later, she gave me her home number and, for the next few weeks, was there to talk with me when I called, often for as much as an hour, some four or five times a week. What she offered me felt like friendship. In fact, I had lucked into a two-for-one deal: a friend and a truly helpful partner in my treatment.

“As I was nearing discharge, I got a third lucky break. Since I had had no visible means of support when I checked into the hospital, it was suggested that I obtain a job before my release. At first uncertain as to how to accomplish this, I decided to call my most recent employer. Telling him I was calling from a psych ward, I explained my dilemma. I said I figured he had probably filled my position but asked if I could come back in any capacity. His immediate response was to let me know that the person who had replaced me was leaving, and to offer me my old job back. This was in spite of the fact that, when I quit six months earlier, I had told him that it was either leave or jump out of my open office window (on the 26<sup>th</sup> floor).

“But it wasn’t only his support and his faith in me that helped; it was also the job, where I stayed for eight years and was repeatedly promoted. Being gainfully employed at a job I enjoyed and where my work was appreciated and respected was enormously satisfying.”

## FACILITATORS AND BARRIERS

In our stories, the personal facilitators and barriers to self-determination are clear: hope versus despair; choice and empowerment versus their absence; effective versus destructive — including forced — mental health treatment; self-confidence versus self-stigma; support from people who believed in us — including peers, mental health professionals and service providers, and employers — versus people who didn’t; and meaningful employment versus a life without meaning. Other important personal facilitators are spirituality (however an individual defines it), and education about oneself, and about one’s illness and symptoms, so that one has more control over one’s own life.

## INTERNAL STIGMA

Key among personal barriers to self-determination is internal stigma — the feeling that there is something wrong with us because society tells us there is something wrong with us. In “Stigma Is Social Death: Mental Health Consumers/Survivors Talk About Stigma in Their Lives,” Deborah Reidy writes: “Internalized stigma . . . refers to the process of

absorbing into oneself negative societal beliefs and expectations held about people who are stigmatized. Many people who have been stigmatized consider this the most damaging effect, because it becomes independent of external perceptions, and can consequently follow one through life, regardless of the external evidence of success or achievement. . . . [Interviewee] Joel Stanley said, 'I feel like I'm alone and carrying this big burden. I will probably never have a life like everybody else, get married, have kids, have a house . . . I feel that I'm over the hill, all used up, nobody's interested in me on any level' " (Reidy 1993).

It is difficult to fight the demoralizing impact of stigma, experts say. According to an article called "The Effectiveness of Stigma Coping Orientations: Can Negative Consequences of Mental Illness Labeling Be Avoided?" (Link, et al., 1991), the short answer to the question posed in the title was No.

The authors examined whether people with mental illnesses could lessen the impact of stigma by common coping mechanisms, ranging from secrecy to openness. They found that these methods produced more harm than good, potentially further isolating the labeled person. "None of these coping orientations were effective in diminishing negative labeling effects on unemployment or on psychological distress/demoralization. In fact, the three coping strategies show consistent effects in the direction of producing more stigma, and with respect to withdrawal-avoidance [avoiding situations in which rejection might occur] this effect is significant."

The authors continued: "Based on these results, we argue that stigma is powerfully reinforced by culture and that its effects are not easily overcome by the coping actions of individuals."

It should be noted that self-stigma is not experienced by everyone who has a psychiatric disability. According to Patrick W. Corrigan and Amy C. Watson of the Chicago Consortium for Stigma Research, ". . . personal reactions to the stigma of mental illness may result in significant loss in self-esteem for some, while others are energized by



prejudice and express righteous anger. Added to this complexity is a third group: persons who neither lose self-esteem nor become righteously angry at stigma, instead seemingly ignoring the effects of public prejudice altogether” (Corrigan & Watson, 2002).

But for those who do experience self-stigma, a major source is the entertainment and news media, which contribute to it in the minds of the general public — as well as in the minds of people labeled mentally ill — by portraying people with psychiatric disabilities as violent and demented, studies show. For example, the National Mental Health Association reported that, according to a survey for the Screen Actors’ Guild, characters in prime time television portrayed as having a mental illness are depicted as the most dangerous of all demographic groups: 60 percent were shown to be involved in crime or violence (three times the average rate). In addition, “[s]tudies showed that as many as 75 percent of stories dealing with mental illness focus on violence (Shain and Phillips 1991). Although more recent research suggests the prevalence of these kinds of stories is diminishing (Wahl, et al. 2002), at least a third of stories continue to focus on dangerousness. Also, the vast majority of remaining stories on mental illness either focus on other negative characteristics related to people with the disorder (e.g., unpredictability and unsociability) or on medical treatments. Notably absent are positive stories that highlight recovery of many persons with even the most serious of mental illnesses (Wahl, et al. 2002) [Corrigan, P.W., et al. (in press)].”

## SYSTEM RIFE WITH STIGMA

Even worse are the negative messages communicated to us by those who are supposed to — indeed, are *paid* to — help us in our journey toward self-determination: mental health service providers. Such messages may contribute most to our internal stigma.

Many of us are familiar with “You and Me,” the poem by Debbie Sesula that has been circulating in the consumer/survivor movement for years  
<[http://www.nisa.on.ca/poetry\\_contest/Hon%20Mention%20Poems/you\\_and\\_me.htm](http://www.nisa.on.ca/poetry_contest/Hon%20Mention%20Poems/you_and_me.htm)>.

“If you’re overly excited, you’re happy; if I’m overly excited, I’m manic,” it begins, and continues: “If you imagine the phone ringing, you’re stressed out; if I imagine the phone ringing, I’m psychotic.” In 21 short lines, it makes an eloquent statement about stigmatizing labels applied by the mental health system to people with psychiatric disabilities.

Some experts have suggested ways to deal with this problem. In an excerpt from their article “Identifying and Overcoming Mentalism,” by Coni Kalinowski, M.D., a psychiatric consultant, and Pat Risser, a former recipient of mental health services and past president of the National Association for Rights Protection and Advocacy (NARPA) as well as a service provider, the two state that, “[t]o truly address the issue of prejudice in the mental health system and have an impact on the system’s participation in discrimination, it is necessary to look at the attitudes and assumptions underlying mental health jargon” (Memorandum, Spring 2003, Resource Center to Address Discrimination and Stigma).

Kalinowski and Risser write: “The language that has become politically charged in the mental health arena includes terms that communicate condescension, blame, and the perception of labeled people as defective.” This language includes obvious terms such as “basket case and loony tune,” as well as seemingly professional terminology, such as “decompensate.” Kalinowski and Risser continue: “ ‘Decompensating’ is an us-them term: under stress ‘we’ may not do well; ‘we’ may cocoon, take to bed, get bummed out, get burned out, get a short fuse, throw plates, scream, call in sick, or need a leave of absence. ‘They’ *decompensate*.”

The authors suggest replacing this term by a brief and accurate description of what’s going on with the person. “For example, ‘After the break-up with her girlfriend, Mary couldn’t sleep. She started pacing at night and complained of hearing voices.’ This brief statement factually describes Mary’s experience and gives meaningful information that begins to suggest interventions that may be helpful.”

Providers who don't believe in their clients' capacity for self-determination are an enormous obstacle to achieving that goal, since it is difficult for the client to avoid internalizing such a negative message. Unfortunately, the fact that the mental health system abounds with discrimination and stigma has been so well documented that it has become axiomatic, and is recognized at the highest levels. For example, "Discrimination and Stigma in the Mental Health System" was one of the topics at "Spring to Action: A National Mental Health Symposium to Address Discrimination and Stigma," sponsored by the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration in March 2001 <<http://www.samhsa.gov/news/newsreleases/010320ma-stigma.htm>>.

#### CONSUMER/SURVIVOR CONSENSUS

Most lists of personal facilitators and barriers to self-determination might resemble what emerged from the "plank sessions" on Recovery at the first National Summit of Mental Health Consumers and Survivors, held in Portland, Ore., in August 1999. The goal of the Summit was to develop consensus around the issues of greatest concern to consumers and survivors and create action plans for future work. Attendees played an active part in developing one or more of the planks, including the Recovery plank <<http://www.mhselfhelp.org/rrecovery.html>>.

(Although self-determination and recovery are not identical, there is enough overlap between the two to make the plank report relevant. Indeed, at least one consumer activist — Terry Grimes of Empowerment for Healthy Minds (EFHM) — would prefer to substitute "self-determination" for "recovery." As Grimes writes on the EFHM Web site: "Most places in the literature where the word 'recovery' is used, phrases like social self-determination, empowerment, ability, and the like could be substituted to positive effect. 'Recovery' might be best suited to conditions like a respiratory infection, heart attack, broken leg, etc. The on-going journey of living with severe mental illnesses is one of the challenges life lets us work with, but it is a trip of empowerment of self, spirit, thought, and caring about others, not just recovering from a disease or broken body" <<http://www.efhm.com/recovdoc.htm>>.)

The Recovery plank participants developed a list of the values and principles most important to recovery, as well as personal barriers and personal supports to recovery. In addition, they developed lists of systemic and societal barriers and supports, which we will not reproduce here.

As selected by vote among the Recovery plank participants, the personal barriers that pose the greatest challenge to recovery (and, we would suggest, to self-determination) include (in order of importance from highest to lowest) fear, low self-esteem/self-confidence, fear of success, negative self-talk, lack of coping skills, personal trauma issues, not knowing your rights, and a feeling of hopelessness.

The personal supports seen as most important to recovery (again listed from most to least important) include relationship with God; friends; online support/chat groups; sex; music; having a regular schedule; diet and exercise; getting in touch with nature: hiking, camping, and gardening; hot bath, whirlpool, Jacuzzi; supportive work environment; helping others; pets; tapping into creative ability; writing and journaling.

Values seen as most important to recovery (same order) include hope, responsibility, spirituality, empowerment, sense of humor, respect, belief in self, compassion, courage, honesty, faith, and love. Principles (same order) include having your basic needs met, a belief in recovery, Humanist philosophy (one definition of which is “any outlook or way of life centered on human need and interest”), employment, education, informed choices, peer support, consumer-run drop-in centers, and ability to advocate for oneself and others.

## HIERARCHY OF NEEDS

The values, principles, and supports that the Recovery plank participants identified bring to mind Abraham Maslow’s “hierarchy of needs.” Maslow hypothesized that people are motivated by unsatisfied needs. He believed that, before “higher” needs — such as “self-actualization,” which he describes as “becoming everything that one is capable of becoming” — can be addressed, lower needs (such as the need for food and other

physiological necessities) must be satisfied. In between are the needs for safety, love/belongingness, and esteem.

Maslow based his theory on his observations of seven contemporaries and nine historical figures — Lincoln, Jefferson, Einstein, Eleanor Roosevelt, Jane Addams, William James, Albert Schweitzer, Aldous Huxley and Spinoza — rather than people with psychiatric disabilities. In fact, he didn't believe anything could be learned from studying such individuals: "The study of crippled, stunted, immature, and unhealthy specimens can yield only a cripple psychology and a cripple philosophy," he wrote in "Motivation and Personality" <http://web.utk.edu/~gwynne/maslow.HTM>. However, his hierarchy seems as applicable to the general public, including people who have psychiatric disabilities, as to the "self-actualized" figures he studied.

#### SPIRITUALITY AND MEANING

Abraham Maslow also believed that people had a need for the spiritual, for something beyond themselves: a "higher power"

<[http://www.mang.canterbury.ac.nz/people/nilakant/spirit/abraham\\_maslow\\_and\\_spirituality.htm](http://www.mang.canterbury.ac.nz/people/nilakant/spirit/abraham_maslow_and_spirituality.htm)>.

However one defines spirituality and meaning, they are clearly important personal facilitators to self-determination and recovery.

For Humanist philosopher Erich Fromm (1900-1980), people make their lives meaningful by living productively, and by using their powers of love and reason to their fullest capacity. For existential psychologist Rollo May (1909-1994), people achieve meaning by being able to live by their highest values, feeling the power of their will to make choices, and being able to love

<<http://www.geocities.com/~webwinds/frankl/meaning.htm>>.

But it is Viktor Frankl's philosophy that truly resonates in regard to the quest for self-determination by people with psychiatric disabilities. For Frankl (1905-1997), who

developed a philosophy/therapeutic method called logotherapy in the 1930s, “meaning” is experienced by addressing the demands of whatever situation one is in, figuring out and committing oneself to one's calling, and trusting in an ultimate meaning, which may or may not be called God. Logotherapy is based on the concept that meaning is more important than pleasure. Unlike Maslow's hierarchy of needs, the philosophy “considers [an individual] as a being whose main concern consists in fulfilling a meaning and in actualizing values, rather than in the mere gratification and satisfaction of drives and instincts” <http://www.geocities.com/~webwinds/frankl/quotes.htm>. Freedom of choice and responsibility are also central to the philosophy, whose main objective is to help people in their search for meaning, regardless of their life circumstances.

Frankl, who spent three years in Auschwitz, believed that how we choose to act in whatever circumstances we find ourselves in is what counts: “Everything can be taken from a [person] but . . . the last of the human freedoms — to choose one's attitude in any given set of circumstances, to choose one's own way.” He also wrote: “This was the lesson I had to learn in three years spent [at] Auschwitz and Dachau: those most apt to survive the camps were those oriented toward the future, toward a meaning to be fulfilled by them in the future” <<http://www.lifeforum.co.za/about%20us.htm>> Although it is not our intention to compare concentration camps to psychiatric institutions, it would seem that logotherapy would have a lot to offer people with psychiatric disabilities in their search for meaning and self-determination.

## SELF-ADVOCACY AS A FACILITATOR

Where do you start your journey to self-determination? One place to start would be to begin to make decisions for yourself, and to learn to be your own best advocate.

Because the National Mental Health Consumers' Self-Help Clearinghouse, an affiliated project of the Mental Health Association of Southeastern Pennsylvania, is committed to helping people with psychiatric disabilities learn to advocate for themselves, the Clearinghouse created the Freedom Self-Advocacy Curriculum

<<http://www.mhselfhelp.org/freedom/index.html>>, which is now part of the Clearinghouse TEAM (Training, Education, Advocacy, Management) training.

The Freedom Self-Advocacy Curriculum focuses on Attitudes, Skills, and Knowledge to help people improve their self-advocacy skills. For example, among attitudes necessary for being an effective self-advocate are believing in yourself, being assertive, and managing your anger. The training includes problem-solving strategies, such as educating yourself, identifying your rights, breaking down the problem, and developing a solution. Such basics as how to identify the right person to talk to, keeping records, and following up are also covered.

Learning to be an effective self-advocate can change a person's life. For example, Maurene Woods, who was trained in self-advocacy skills by Advocacy Unlimited, Inc., in Wethersfield, Conn., a consumer-run advocacy educational program, has said: "Before I went into the program, I had been hospitalized constantly for major depression and post-traumatic stress disorder; I was extremely intimidated by the mental health system; I was not able to advocate for my own rights or play an active role in my own treatment plan." In fact, she said, she didn't even know what rights or options she had. "I was lost in the system, and the system was not helping me. I hadn't worked in probably three years."

But less than a year later, Wood was employed full time as a respite worker in a residential program and was completely self-supporting. "I think I'd still be lost if it hadn't been for graduating from that program," she told the Clearinghouse newsletter ("Experts: Self-advocacy training is vital to consumer empowerment," *The Key*, Spring '98, Vol. 4, No. 2).

Self-advocacy can encompass everything from simply speaking up for ourselves in regard to decisions that affect our daily lives, all the way to advocacy for systems change, since that, too, has an impact on our lives.

Something else we can do to facilitate our self-determination is to create an advance directive <<http://www.protectionandadvocacy.com/adintro99.htm>>. Advance directives allow individuals to specify the treatments they would accept — and those they would not accept — should they be in a position where they cannot speak for themselves. They let us have greater control over our lives, and can give treatment providers important information that can guide them to providing the best quality of care. You can also name another person, someone you trust, to make decisions for you in the event that doctors determine that you do not currently have the capacity to make informed choices on your own. (This is called a Durable Power of Attorney.)

## COMMUNITY ORGANIZING

Devoting ourselves to furthering the movement for social change is an important route to self-determination, since such efforts can give our lives real meaning. The consumer/survivor movement, which began more than 30 years ago as an offshoot of the civil rights movement, needs every one of us!

Besides the goals of effecting social change and having a positive impact on our own lives and the lives of others, a byproduct of being involved in the movement is peer support — more simply described as friendship with people who have shared our experiences. Peer support has been proven to promote self-determination. Another effect of working toward social change is the feeling of empowerment engendered by such activity.

## JOSEPH ROGERS:

“When I was working as a mental health service provider in the late 1970s in northern New Jersey, I became involved in a statewide community organizing effort and met Judy Banes, a “peer.” Encountering one other person who was not only recovering from mental illness but was also working to effect social change made a big difference in my ability to see that I could not only struggle toward my own recovery but I could do this in a way that would help others and thereby help myself. I found this therapeutic.



“Judy Banes and I organized a demonstration to call attention to some problems at a large psychiatric hospital in the area. Everyone on the picket line was either a current or former patient of that particular institution. All we did was walk in a circle and chant slogans about improving the conditions. It seemed a fairly insignificant effort at the time.

“Then, several years later, during a presentation I made on organizing the movement for social change, someone said he had been on that picket line and that it had transformed his life. Before that, he had been cycling in and out of the hospital. Afterwards, he became active in the movement, and is now operating a consumer-run service in New Jersey.

“He’s not alone: I’ve heard dozens of stories like this from people who credit the experience of walking in a line to protest injustice with helping them realize they could start in a new direction and not continue in their role as ‘mental patient.’ ”

Experts, such as renowned community organizer Saul Alinsky (1909-1972), have noted that encouraging people to confront oppression and to realize that they don’t have to accept the status quo is one way to help them become more resilient and “self-determining.” Not everyone needs to join a picket line. Sometimes just connecting with a peer who has lived through similar experiences can make someone realize that he can change his life and begin to work toward self-determination and recovery. Twelve-step groups are well-known for helping people with substance abuse disorders to achieve this understanding. It may be more difficult for someone with a psychiatric disability to make the kind of immediate change that someone can achieve just by stopping drinking or drugging. But helping people awaken to the fact that self-determination is possible and that they themselves must play a major role in their own recovery should be a major part of the effort at instituting self-determination as a theme in the way consumers get help.

## PEER SUPPORT

Many distinguished researchers have noted the importance of peer support to the recovery process. One such researcher is Dr. Courtenay Harding, executive director of Boston University's Institute for the Study of Human Resilience and an author of a landmark study of deinstitutionalized people with psychiatric disabilities in Vermont and Maine who had spent years warehoused in the back wards of mental institutions.

“Consumers are wonderful at helping each other, and teaching each other how to take control of their illness,” she told *People First*, a publication of the Pennsylvania Office of Mental Health and Substance Abuse Services.

The Vermont-Maine study, involving people with serious mental illness, began in the mid-1950s, when 269 people were released from the back wards of Vermont State Hospital and provided with a model rehabilitation program in the community. Thirty years later, 262 of the 269 were located and assessed and it was found that approximately two-thirds of them had achieved significant levels of recovery. This was in contrast to a matched control group of patients released from a Maine state hospital, who had received more traditional treatment and who had not done as well in the community.

“We looked at what happened to them over three decades: who was working and who wasn’t, how independent and well-functioning they were, how many symptoms they had,” said Harding. “The Maine group showed up over the long haul as having many more symptoms, much less employment, and much lower levels of functioning in the community than the Vermont group.” Harding added that the principal difference between Maine and Vermont was that “Vermonters got a whopping psychosocial rehabilitation program and Mainers did not.”

As a result of the study, she said, “We have very strong data showing that community integration, rehabilitation and self-sufficiency models — which was what the Vermonters had — are far superior to the Maine model of medication, entitlements, maintenance and stabilization” (“Recovery Gains Acceptance,” *People First*, Vol. 9, No. 2, Fall 1999).

## PEER SUPPORT AND PSYCHIATRIC REHABILITATION SERVICES

Self-determination is the basis of all consumer-run programs

<http://www.mhselfhelp.org/pubs/key/fa02/nfc.html>. If people with mental illnesses are going to move toward recovery rather than languish in programs that are often little better than institutions, consumer-run services are an indispensable component of the “continuum of care.” They are often successful in reaching people who have been wary of more traditional services.

Conversely, an obstacle to self-determination is the lack of support for programs such as these and other kinds of psychiatric rehabilitation programs

<http://www.apa.org/monitor/feb00/schizophrenia.html> — designed to improve living skills and to assist people with disabilities in realizing their potential for independence and for useful and productive activity, such as work — that have proved successful in increasing the overall quality of life, independence, employment, social supports, and education of consumer/survivors.

## CONCLUSION

Because systemic and societal barriers and facilitators have been so central to our respective efforts to achieve self-determination — and because there is so much overlap among personal, systemic, and societal factors — it has been difficult to limit our discussion only to barriers and facilitators that are strictly personal, as we had been asked to do. But we have done our best to stay within those limits and, at the same time, give an overview of what we believe is helpful or harmful to anyone’s quest for self-determination.

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# Run for the Stronghold: The Story of One Survivor's Source of Self-Determination – Self-Acceptance and Love

***By Sarah Triano, Co-Founder, National Disabled Students Union***

***“We need to tell the world, starting with ourselves, who we are and what we are, and it will give others the insight and courage to open up their hearts and minds as well.”  
– Jodi Ross***

In the spring of 1992, when I was seventeen and preparing for my high school graduation, the movie *Thunderheart* starring Val Kilmer was released. As a young woman with a disability, I was immediately drawn to this film – and for more reasons than just Val Kilmer. The film tells the story of an FBI agent with Sioux background, Ray Levoi, who is sent to a reservation to help with a murder investigation. During the course of the film, Ray solves the murder investigation, but more importantly, he also begins to wrestle with and discover his true identity. While he is at the reservation, Ray undergoes a transformative process during which he rejects the intimidating tactics and culture of his fellow FBI agents, learns about his Sioux heritage, and in turn, begins to embrace part of his true identity – the one he has been alienated from all his life – his identity as a Sioux. To get to this place of self-acceptance and self-love as a Sioux, however, Ray must first “go to the source.” Toward the end of the film, when Ray is struggling with the contradictions inherent in the different aspects of his identity, Grandpa Sam Reaches, the medicine man, tells him the story of Wounded Knee and how one man named Thunderheart was shot running for the stronghold. “It's his blood that runs through your veins, like a buffalo, “Grandpa says to Ray. “Thunderheart has

come to this troubled place to help his people. Run. Run for the Stronghold, Thunderheart, the soldiers are coming."

Soon after the release of *Thunderheart*, I too "ran for the stronghold" when I was invited to participate in the nation's first Youth Leadership Forum for High School Students with Disabilities in California. Like Ray, I was a member of a large community – the Disability community – but did not know the first thing about my community, or about my history and culture as person with a disability. I was diagnosed with a hereditary and incurable primary immune system disorder called Selective IgA Deficiency when I was thirteen, and later in life acquired the diagnoses of Obsessive Compulsive Disorder and Post-Traumatic Stress Disorder. Due to the insidious discrimination I experienced in school while growing up – such as the time in high school when another student glued a sign to my car windshield that read, "MENTALLY HANDICAPPED" – the message sent to me was very clear: as a person with a non-apparent disability, I had to do everything I possibly could to hide my disability and avoid contact with other disabled people. I had to pass and pretend like I did not have a disability if I was going to survive. I was deeply ashamed of myself and my disability. Here I was just seventeen - so young, and yet already ashamed to be who I was – I was ashamed to be disabled.

So when I arrived at the California Youth Leadership Forum for Students with Disabilities in 1992, I would not even shake hands with the other disabled people I met, let alone embrace them as sisters and brothers in a community. I will never forget that first day of the forum. As I was surrounded by all these disabled people, I sat there thinking to myself, "What am I doing here? I don't belong here. / don't have a disability.

I've *overcome* my disability!" Like many others with disabilities, I had "internalized the public's fear and devaluation of disability" and had been socialized to "reject people with disabilities as valuable companions" (Gill, 1997). By the end of the leadership forum, however, it was a completely different story. In less than a week, I went from being an isolated young woman who was ashamed of myself and a fundamental part of me - my disability - to being a member of a vibrant Disability community, fully confident in myself, my capabilities, and my worth as an equal human being. Like Ray in *Thunderheart*, at this youth leadership forum, I underwent a life-changing, transformative experience; an experience that not only led me to question and reject the societal definition of "disability" as a deficiency, but also an experience that taught me about my heritage and culture as a person with a disability; and an experience that ultimately led me to "the source," my personal "Stronghold": knowledge, acceptance of, and pride in my true identity as a disabled woman.

After I left the Youth Leadership Forum for Students with Disabilities in 1992 and shared my life-changing experience with others in an effort to better understand and explain it, people kept throwing the word "self-determination" at me. I had no idea what this big fancy word meant, and apparently neither did anyone else because no one could explain it to me when I would ask. The word "self-determination" to me was like "supercalifragilisticexpialidocious." "Even though the sound of it is something quite atrocious, if you say it loud enough you'll always sound precocious." It seemed to be one of those words – like "truth" – where everyone thinks they know what it is but no one can really define it. It means, at the same time, both everything to everyone, and nothing to no one. People kept telling me that what I experienced at the youth



leadership forum was part of the process of self-determination. I didn't know anything about any "self-determination," but what I did know was that I no longer felt a deep sense of shame about myself and my disability, and that I had finally begun to accept and love every aspect of myself, including those parts of my identity that are stigmatized by the majority culture. If that was what "self-determination" was, then so be it – consider myself "self-determined."

As I read the different definitions and principles of "self-determination" in the literature, however, none of them seemed to adequately capture my experience at the leadership forum or resonate with me at all as a person with a physical and psychiatric disability. All of the existing definitions of "self-determination" today seem to embody the values of Western culture (values such as "control," "choice," "independence," and "freedom") and focus on things that are external to the individual. Few, if any of these definitions mention what is arguably one of the most important aspects of self-determination: experiences that lead a person to what I call "the source," the personal "Stronghold" – knowledge, acceptance of, and pride in every aspect of one's true identity, what Dr. Carol J. Gill refers to as "disability identity development" (Gill, 1997).

There is nothing new about this theory on the importance of identity development in self-determination, nor is it unique to individuals with disabilities. As Sandra Lee Bartky notes in her book, *Femininity and Domination*, "'Feeling inadequate' may color a person's entire emotional life. Under conditions of oppression, the oppressed must struggle not only against more visible disadvantages but against guilt and shame as well. It was not for nothing that the movement for black empowerment called not only for black civil rights and economic advancement, but for 'black pride'" (Bartky, 1990). In his

final published work, in fact, Dr. Martin Luther King, Jr. outlined what he considered to be one of the most serious barriers for black people in American society, what he referred to as “cultural homicide.” “One must not overlook,” he wrote, “the positive value in calling the Negro to a new sense of manhood, to a deep feeling of racial pride and to an audacious appreciation of his heritage. The Negro must be grasped by a new realization of his dignity and worth. He must stand up amid a system that still oppresses him and develop an unassailable and majestic sense of his own value. He must no longer be ashamed of being black” (Martin Luther King, 1967).

Thirty-five years later, the “cultural homicide” of diverse people everywhere continues, and is particularly apparent among people with disabilities. Even though I have never felt the sting of racial discrimination, as a young woman with a physical and psychiatric disability growing up in America, I know first hand what it feels like to be ashamed of being disabled. I know what it feels like to live in a society where the contributions of disabled Americans are largely ignored. And I know what it is like to be stripped of my personhood by a culture that defines “disability” – a fundamental part of who I am – as a deficiency, disadvantage, and limiting impairment. Although there are many barriers facing people with disabilities today, the single greatest obstacle we face in our struggle for self-determination is our own sense of inferiority, internalized oppression and shame. All you have to do is ask any disabled person today how they feel about themselves or how they define “disability” to know that the sense of shame associated with having a disability has reached epidemic proportions. I direct the nation’s first locally-based Leadership and Organizing Training Program for Youth with Disabilities at Access Living in Chicago, and in my work with disabled youth I am struck

by the overwhelming sense of shame they live with on a daily basis. Some of these youth will not even admit they have a disability, let alone take pride in it. Yet, according to existing definitions of “self-determination,” they are doing just fine. These youth are, for the most part, “controlling their lives,” “reaching goals they’ve set,” and “taking part fully in the world around them,” but deep down inside they hate themselves, or at least one aspect of who they are – in particular, their disability. That hardly seems like “self-determination” to me. How can you fight for freedom if you don’t feel you have worth as a person deserving freedom? As Dr. Carol J. Gill notes, “The attempt to fashion an identity that excludes important parts of the self, i.e. the disabled parts, then, results in a sense of self in conflict or a self-image riddled with significant gaps. In either case, the resulting identity is not sufficiently sound to support stable, resilient self-esteem. Without stable self-esteem, it is difficult for the individual to sustain her/his sense of worth and entitlement to a place in society” (Gill, 1997).

The Disability rights movement has made many gains in the area of civil rights over the past decade, but what good is an Americans with Disabilities Act, an Individuals with Disabilities Education Act, or a Section 504 if people will not exercise their rights under these laws because they are too ashamed to identify as being disabled? Socialized by non-disabled society to think of ourselves as worthless, many people with disabilities are too demoralized to lay claim to the legislated rights we already have. “As long as the mind is enslaved,” Dr. King wrote, “the body can never be free.” As long as people with disabilities remain ashamed of who we are, we will never realize the freedom we often refer to in existing definitions of “self-determination.” We

must first learn about, accept, and take pride in our true identity as disabled people. We must no longer be ashamed of being disabled.

Dismantling centuries of internalized oppression, however, and finding ways to accept and love ourselves, and learn about our true identity as disabled people is easier said than done. Unlike other historically oppressed minorities, people with disabilities do not always have the benefit of a generational transfer of disability history and pride through the family structure. There are no “disability churches” per se, neighborhood enclaves, or other communal institutions where we can consistently receive positive messages about disability that counteract the depredation wrought by the onslaught of cultural terrorism. There is a tremendous need for our community to create safe spaces that promote this important foundation of self-determination; safe spaces where disabled individuals can come together and develop the inner strength and true identity that can only be found by knowing who you are, knowing what you are (what you believe and why), and knowing where you want to go and how to get there.

### ***KNOW WHO YOU ARE: THE IMPORTANCE OF KNOWING YOUR HISTORY AND CULTURE AS A DISABLED PERSON***

No one understood the importance of self-acceptance and love in the process of self-determination more than the great leader, Malcom X. According to Cone (2000), the dominant theme of Malcom X’s ministry was unity, and “unity depended on genuine love for each other.” “If blacks were going to achieve the unity necessary for the attainment of their freedom,” Cone writes, “then self-hate – according to Malcom the number one problem in the black community – had to be replaced with a love of themselves.

However, genuine love of each other was possible, in Malcom's view, only to the degree that blacks were able to acquire a true knowledge of their history and culture. Malcom told blacks that they were 'culturally dead,' alienated from their past and from each other. That was why they did not love each other and could not achieve the unity that was necessary for their freedom" (Cone, February 2000). As Malcom X so astutely noted, knowledge of one's history and culture is an essential component of self-love, unity, and the ultimate attainment of freedom. Like many other oppressed minority communities, however, people with disabilities have been systemically stripped of our history and culture. Even today, there is little, if any, mention of Disability history in schools, colleges, and university history courses and most people are hard pressed to even name one significant figure in Disability rights history. Not only is the dominant society stripping us of our history and culture, however. The gap in the historical record regarding disability is also being used against us to strip us of our civil rights. On February 21, 2000, the Supreme Court ruled in *Board of Trustees of the University of Alabama v. Garrett* that lawsuits under Title I of the Americans with Disabilities Act for damages against states are unconstitutional. In their ruling, five justices said there were only "unexamined, anecdotal accounts of adverse, disparate treatment" of people with disabilities "by state officials" in the historical record. This, in spite of a large collection of state statutes, session laws, and constitutional provisions that illustrate pervasive state-sponsored discrimination against persons with disabilities, dating from the late 19th century to the present, compiled by over 100 historians and scholars (online, Sept./Oct. 2000). Disabled people have been alienated from our history and culture and we are paying dearly for it.

We are not only paying for it with our civil rights, however. We are also paying for it with our lives. In April of 2003, a 7 year-old girl with a learning disability in Connecticut named Sara was shot in the chest while sleeping with a .30 caliber rifle by her mother (Zielbauer). Less than 3 months later in July, in New York an 8 year-old disabled girl named Stephanie mysteriously died and her foster mother put her in a garbage bag and dumped her on the sidewalk (Brick & Kaufman). And in August of 2003, in Minnesota a 6-month old baby girl with Down Syndrome named Raya was killed by her mother when she slit Raya's throat twice with a kitchen knife (Donovan & Pina, 2003). All three of these disabled children's deaths have largely gone unnoticed by the general public and by the Disability rights movement in the U.S. Perhaps if we were more attuned to our history and culture, we would recognize this modern-day infanticide as a continuation of the eugenic thinking of the 20th century that resulted in the sterilization, institutionalization, segregation, social degradation, and economic exploitation of disabled people. Perhaps if the dominant culture were more attuned to Disability history and culture, parents of Disabled children would realize that Disabled people can lead fulfilling lives just like others, and that Disabled people have fought valiantly, contributed a great deal to our nation's history, and have maintained our humanity through centuries of the most unimaginable oppression. Perhaps if we were not alienated from each other as a community of people with disabilities – and so consumed with reactionary tactics to divisive policies created by and for non-disabled bureaucrats, we could unite together and fight for the one inalienable right that all human beings should have: the fundamental right to life. Like African-Americans before us, however, many people with disabilities today continue to be alienated from our past and from each other, which

contributes to our on-going self-hatred. As Malcom X taught, this self-hatred must be replaced with self-love if we are to achieve the unity necessary for the ultimate attainment of our freedom. Any meaningful definition of “self-determination,” therefore, must include reference to the importance of self-acceptance and love, and the role of knowing one’s history and culture in the attainment of that self-love.

### ***KNOW WHAT YOU ARE (WHAT YOU BELIEVE AND WHY): THE IMPORTANCE OF SELF-DEFINITION***

As a disability rights activist, I am constantly amazed whenever I meet other self-advocates – persons who would be considered by most as highly “self-determined” individuals – who have never stopped to think about what their personal definition of “disability” is. When I ask them, “What is the first thing that comes to your mind when I say the words “disability” or “disabled,” most of them are caught off guard and hard-pressed to provide a non-stigmatizing definition that is different from the definition of “disability” in the dominant culture.

According to *The American Heritage Dictionary of the English Language*, “disability” is defined as “a disadvantage or deficiency, especially a physical or mental impairment that interferes with or prevents normal achievement in a particular area, or something that hinders or incapacitates.” This definition of “disability” is paralleled in most of the civil rights laws today that protect the rights of people with disabilities, including:

- **Definition of “Disability” Contained in The Rehabilitation Act and The Americans with Disabilities Act:** “Any individual who has a physical or mental impairment which substantially limits one or more of such person’s major life

activities, has a record of such impairment, or is regarded as having such an impairment.” In other words, you are limited in what you can do *because of your disability*.

- **Definition of “Disability” contained in the Individuals with Disabilities**

**Education Act:** “A physical or mental impairment that ‘adversely affects a child’s educational performance.’” In other words, you can’t learn *because of your disability*.

- **Definition of “Disability” contained in the Social Security Act:** “‘Disability’ means ‘inability to engage in any substantial gainful activity...’” In other words, you can’t work *because of your disability*.

- **Definition of “Disability” contained in the Developmental Disabilities Act:** “A ‘developmental disability’ is a severe, chronic disability of a person five years of age or older which - is attributable to a mental or physical impairment or combination of mental or physical impairments; is manifested before the person attains age twenty-two; is likely to continue indefinitely; results in substantial functional limitations in three or more of the following areas of major life activity: A) self-care, B) receptive and expressive language, C) learning, D) mobility, E) self-direction, F) capacity for independent living, and G) economic self-sufficiency....” In other words, you basically cannot do anything *because of your developmental disability*.

Labeling people with disabilities by medical categories, and attributing the problems we experience in society to our disabilities, or to an internal “deficiency or abnormality” as disability is often perceived, is antithetical to the philosophy and goals of



the disability civil rights movement. According to the prominent Disability Studies scholar and activist, Carol Gill (1998), the experience of disability has been historically viewed as a “tangible flaw located within an individual’s physical or mental constitution.” This view comprises what has been commonly referred to as the “medical model of disability.” With the passage of Section 504 of the Rehabilitation Act in 1973, however, disability rights activists and others began articulating a “social model of disability” which de-emphasizes “the significance of individual impairments (such as, paralysis, blindness or learning limitations) in causing the problems persons with disabilities face” (Gill 1998). It focuses, instead, “on such socially constructed barriers as exclusion, blocked access and disability prejudice as the ‘real’ problems of disability” (Gill, 1998).

According to a social model of disability, therefore, the educational difficulties experienced by disabled children in the classroom are not necessarily caused by their individual disabilities, but are rather the result of a poorly-structured education system that is not equipped to meet the needs of a diverse student population. The barriers experienced by people with disabilities in society are not necessarily caused by our disabilities, but are rather the result of living in a society that is designed by and for non-disabled people.

In my travels as a disability activist, I have asked many people across the country what the first thing is that comes to their mind when they hear the words “disabled” or “disability.” Without exception, the responses of most people (disabled and non-disabled alike) reinforce the dominant culture’s views of disability: “pathetic, weak, unable, not able, a barrier, a challenge, something that prevents you from doing something, not normal, a wheelchair.” In one instance, a woman said to me, “I have a disability. I’m

black.” She went on to explain that because of her skin color, she has experienced many barriers and challenges in the dominant white culture. The other typical response I get is, “Well, we all have some kind of disability.” In fact, the first time I heard this “we all have a disability” argument was when I was at the National Leadership Development Conference for Students with Disabilities in Washington, DC in 1998. One of the speakers, a noted Congressman, made the following argument during his speech at the conference: “We all have a disability, don't we? After all, I'm not 6 foot 2 and can't dunk a basketball like Michael Jordan, so in a sense, I have a disability, right?”

I was upset when I heard him say this, but at the time I couldn't quite express why. My comrade in the National Disabled Students Union, Kathy Coleman, expressed my feelings beautifully when she said, “The ‘everyone has a disability’ argument doesn't sit well with me either. I had a professor in a course say her disability was that she could ‘not spell when she was writing on the board in front of the classroom’ as her way of making an argument for the ‘everyone has a disability’ viewpoint (she does not have a learning disability). There is a difference between being weak at a skill and having a disability. Everyone has strengths and weaknesses that are not a disability. You don't get denied health insurance because you make a mistake spelling on the chalk board.” Similarly, I seriously doubt this Congressman has ever been denied health insurance or the right to equal education because of his “disability.”

Fundamentally what is at issue here, to me, is the definition of disability. Certain people define “disability” as a “limitation,” a “weakness,” a “barrier to be overcome.” If that is how you define “disability,” then yes, we all have a disability because we all have barriers and challenges we must overcome in our lives, including discrimination and all

the other “isms.” But I do not define disability that way. Over the years, I’ve come to define disability as a natural and beautiful part of human diversity that people living with disabilities can take pride in. I believe the barrier to be overcome is not my disability; it is societal oppression and discrimination based on biological differences (such as disability, sex, race, age, sexuality, etc). Today, it would be ludicrous to define the experience of being a woman as an “impairment that substantially limits one or more major life activities.” We would be outraged if the laws guaranteeing equal education for African-American children explicitly stated that an African-American child is only protected by the laws if the child has a skin color that “adversely affects their educational performance.” We would laugh if we heard a white person say, “I understand what you are going through because, after all, we’re all Latino, aren’t we?” How often do you hear a civil rights activist boast about the fact that they have “overcome their skin color”? Do they hold out for that “cure” for their skin color, like Christopher Reeve does with his disability? Do African Americans try to “overcome their blackness,” or understand that the primary barriers for their community in our society are racism and discrimination? Why is it somehow different for disability? “When disabled people internalize the demand to ‘overcome’ rather than demand social change, they shoulder the same kind of exhausting and self-defeating ‘Super-Mom’ burden that feminists have analyzed” (Linton, 1998).

It is time that we reclaim the definition of “disability,” take control over the naming of our own experience, and acknowledge self-definition as an important part of self-determination, just as African-Americans and women did before us. In 1966, for example, during his historic speech in Berkeley, Stokely Carmichael defined the

concept of Black Power as a fundamental right to define oneself and to be free of the oppressive black/white opposition in society. "The lie that says anything black is bad." "People have been telling you anything all black is bad," he said, "I'm never going to be put in that bag. I'm all black and I'm all good" (Carmichael, October 1966). Carmichael's refusal to be subjected to a black/white dichotomy through a purposive reversal of values harkens back to a strategy of inversion articulated over a century before by Frederick Douglass: "What [my master] most dreaded, that I most desired. What he most loved, that I most hated. That which to him was a great evil, to be carefully shunned, was to me a great good, to be diligently sought; and the argument which he so warmly urged, against my learning to read, only served to inspire me with a desire and determination to learn" (Douglass, April 28, 1845). In 1978, the well-known lesbian feminist, Mary Daly, employed a similar strategy of inversion in her book, *Gyn/Ecology*, by arguing that a woman whom the patriarch calls "evil" is in fact good, whereas a woman whom the patriarch calls "good" is in fact bad (Daly, 1978).

Uniting all three of these strategies of self-determination is an attempt to subvert the cultural imperative to structure experience through false dichotomies such as white/black, man/woman, straight/gay, able/disabled, etc. According to the lesbian theorist, Judith Butler, the Western philosophical tradition is largely driven by a binary system that defines certain terms, such as masculinity, by virtue of their negative, contrasted opposite (i.e. femininity), thereby producing a series of binary oppositions that serve to solidify meaning, beliefs, and what is perceived to be reality, or the "truth" (Butler, 1993). Elizabeth Grosz argues that this "dichotomous thinking necessarily

hierarchizes and ranks the two polarized terms so that one becomes the privileged term and the other its suppressed, subordinated, negative counterpart:

The subordinated term is merely the negation or denial, the absence or privation of the primary term, its fall from grace; the primary term defines itself by expelling its others and in this process establishes its own boundaries and borders to create an identity for itself. Body is thus what is not mind, what is distinct from and other than the privileged term (Grosz, 1994).

These oppositional terms, therefore, do not coexist on equal grounds; rather, one side of the binary opposition is privileged, while the other side is devalued (Schrift, 1995). In the system of signification, or representation, then, Awhite@ becomes the privileged term - the signifier - that defines itself by its suppressed, subordinated, negative opposite: Ablack,@ the signified. As Grosz notes, this subject/object divide serves a very specific linguistic and cultural purpose, particularly in terms of establishing the boundaries necessary for the creation of a seemingly stable cultural identity. According to Rosemarie Garland Thomson, the dominant culture=s identity, or Aideal self,@ Arequires the ideological figures of the woman to confirm its masculinity and of the black to assure its whiteness,@ just as it also requires the disabled Ato secure its able-bodiedness.@ AThe freak, the cripple, the invalid, the disabled,@ she writes, Alike the quadron and the homosexual - are representational, taxonomical products that naturalize a norm comprised of accepted bodily traits and behaviors registering social power and status@ (Thomson, 1997). Those who are situated in the position of the negative, subordinated Aother@ (i.e. the black, the woman, the disabled, etc.) are not allowed to participate in

this process of representation and to offer their definition of what it means to be black, feminine, disabled. Instead, as the Aconstitutive outside,@ they are subjected to an explicit narration of their bodies that in and of itself serves to erase any Adisruptive possibilities@ or alternative definitions (Butler, 1993). As the French feminist, Luce Irigaray, notes, when these isotopical feminine figures are taken to be *the* feminine, the Areal@ feminine (i.e. femininity as defined by the Aother,@ the woman) is fully erased by its very representation as the negative, contrasted opposite of masculinity (cited in Butler 36). This dichotomous representation then becomes a Areality@ that people act upon as if it were true - a sign that supposedly references the world without any complication or ambiguity.

As many feminist theorists have shown, however, this sign is highly unstable. That which we believe to be Anatural@ or inherently Atrue@ (i.e. that black is the negative opposite of white) is nothing more than an illusion of language, an imposed fiction that only appears stable and absolute because it has been repeated and reified from one generation to the next. Once it is recognized that *meaning is not fixed*, and that the relationship between the signifier and the signified is an arbitrary product of language, Butler argues that it is then possible to interrupt the site of signification and directly challenge the assumption that what we believe to be true is inherently true by *developing alternative definitions* that transgress the binary oppositions of white/black, masculine/feminine, form/matter, mind/body, etc. Grosz notes, however, that when dissolving these oppositional categories, Awe cannot simply ignore them, vowing never to speak in their terms again.@ AThis is neither historically possible nor even desirable,@

she writes, insofar as these categories must be engaged with in order to be superseded (Grosz, 1994).

Many disabled people today propose that we choose a new name for ourselves and our community rather than “disability” such as “physically challenged,” “disAbility,” “the able disabled,” and “special needs.” As Grosz notes, however, these terms do not necessarily challenge the oppositional category of able/disabled” nor do they really fundamentally change how people define “disability.” As Stokely Carmichael, Frederick Douglass, and Mary Daly all illustrate, one of the most effective ways to directly engage, and thereby supersede, this dichotomous category is to invert the subject/object divide and effectively mobilize it to its opposite by purposely valuing that which is devalued. We must, as Grosz argues, engage the language that has been historically used to stigmatize us, “disabled,” and reclaim and reassign its meaning by purposely valuing that which is devalued (“disability”).

What I am proposing – a fundamental redefinition of “disability” both individually and in society – is extremely radical and strikes at the deepest feelings and assumptions people have about themselves and the nature of life itself. As one of my comrades in the National Disabled Students Union, Jodi Ross, said: “The mindset of oppression is pervasive, has a momentum of its own and takes a lot of energy to get free of. So even people who have quite a few insights and positive qualities and even care about you/me/us in some genuine ways are often still very caught up in it and very unsettled when its challenged. But unfortunately, I don't think there is a chance in hell that the able-bodied population will get this until we get it ourselves. There are MANY - I would say MOST- who are disabled who share the belief that they are lesser and that

disability is by definition tragic and bad. Even disabled people who I personally consider amazing and wonderful and even people who are politicized about other oppression, still believe the lies about themselves and their disability. This is a common problem in oppressed populations: internalized oppression. I think it's worse among disabled people because our movement is so little known and because many of us grow up in families where the folks who are supposed to love us best buy into the idea. As a lesbian, I can say that this is a common problem for other minorities who live in a situation of being "the only one" in their family, in a world that affirms the 'defective' status of 'people like me,' as well. But it's not hopeless. Dykes, gay men, and other sexual minorities have worked hard over ages and made considerable progress. The suicide rate for gay teens is still many times that of straight ones, but there are many more people coming out and finding self-love, community, and the respect of others than in the past. We need to do the same in the disability movement. We need to show models of empowerment, not only for practical reasons, but also because humans are social creatures and don't like to be alone in their thoughts any more than we like to be alone in our bodies. We need to tell the world, starting with ourselves, who we are and what we are, and it will give others the insight and courage to open up their hearts and minds as well."

### ***KNOWING WHERE YOU WANT TO GO AND HOW TO GET THERE***

As Jodi Ross notes in her insightful comment, a fundamental part of self-determination is knowing who we are and what we are (i.e. what we believe). Without this foundational knowledge of self and identity, knowing where you want to go and how



to get there (what is traditionally considered “self-determination”) is next to impossible. As the legendary civil rights activist, Grace Lee Boggs, wrote in her autobiography, “To make a revolution, people must not only struggle against existing institutions. They must make a philosophical/spiritual leap and become more *human* human beings. In order to change/transform the world, they must change/transform themselves” (Boggs, 1998).

All Disabled people must learn to go out into the world with our heads held high, with our dignity and pride intact, vowing to *take back* the definition of disability with *militant self-pride*. Just as “Black is beautiful,” *Disability is beautiful* and we should never let anyone tell us any differently or make us feel ashamed to be who we are. Today marks the beginning of our efforts to develop a whole community of people with Disabilities and allies who are proud to be who we are, who do not see ourselves as victims, who expect more from ourselves and those within our community, and who are committed to building an inclusive community that recognizes the dignity, humanity, and worth of *all* people. In our efforts to promote “self-determination,” we must prioritize the transformation of the hearts, minds, and souls of our people, for that is where our true power lies. As the great leader of our movement, Ed Roberts, once said, “My ability to regain the pride in myself as a person with a disability is one of the most important things that's coming out of what's happening here today.” Whether or not Ed Roberts and his comrades successfully won regulations for Section 504, they left that effort with a fundamental self-acceptance and love, a new sense of pride in who they were - and that is their legacy and our heritage; a heritage that I embrace and value with every fiber of my being; a heritage that is truly my “source” of self-determination, my personal

“Stronghold” today as a young, proud, disabled woman. “Run. Run for the Stronghold, Thunderheart, the soldiers are,” indeed, “coming.”

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# THE ROLE OF INFORMATION & COMMUNICATION TECHNOLOGY IN PROMOTING MENTAL HEALTH CONSUMERS' SELF-DETERMINATION

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## Introduction

Recently I have been training a group of practitioners in a welfare-to-work program on the topic of mentoring. We talk about all the issues the program's customers raise in the course of their incredibly challenging transition from being welfare recipients to being employed and self-sufficient providers. During a recent session a number of participants shared the concern that their customers often report some degree of depression, and they did not know how to respond, how to determine the severity of the problem, or how to advise the customers.

One young staff person, who had lived in Nigeria, offered the perception that this trend was part of a tendency in our U.S. culture to convert experience – such as a headache, for example – immediately into a diagnosis, and then to address it right away with a medication. In Nigeria, she said, rather than responding to a headache with a pill, the typical response would be to take a cup of tea or a nap.

She asked my opinion as to whether Americans are disposed to depend on and believe in drugs as the answer to everything. I replied that I think that our culture reveres technology, and that pharmaceuticals are just an instance of technology. In fact, I ultimately did address the staff's need for guidance on responding to customers' reports of depression by turning to technology for help, but that is another story for later in this paper. This story is meant to imply the caveat that, while technology can be a tool and a powerful asset, with the perspective of a certain distance one can see that over-identification with the technology can make it a substitute for experience-based responses that honor our ability and responsibility to determine our own life choices and who we are as individuals. Like the tourist who subordinates her vision to the camera's lens, a person may become less than a fully realized person if he invests so much in technology that it comes between himself and his immediate inner and outer experience.

Acknowledging this caveat, we address in this paper the ways that information and communication technology can and do promote self-determination among mental health consumers. The primary aims will be: to show within the frame of a proposed conceptual model concrete ways that technology use *can* support self-determination; to review evidence suggesting that technology use does promote self-determination; to uncover real and perceived challenges, barriers, and pitfalls that confront individual mental health consumers who use or might wish to use technology; and to offer practical information, resources, and strategies for surmounting those difficulties.

### **An Operational Model: Awareness → Choice → Efficacy**

In this examination, we will construe self-determination to be the operational result of a set of conditions applying to an individual: first, awareness – the state of being informed about the range of alternatives relevant to a problem to be solved or objective to be achieved; second, the perception and reality in the life of an individual that s/he has a free choice among the identified alternatives; and, finally, a sense of efficacy, i.e., the power and means to implement a choice once it is made, and thereby to have an effect on one's own life. By this model, factors that facilitate awareness, choice, and, most critically, the sense of efficacy promote self-determination.

It has been recognized that the sense of efficacy is so often undeveloped in people with mental illness and with disabilities in general. Sands and Wehmeyer make this connection, describing it as "...an all-too-frequent consequence of the absence of choice and control: Individuals with disabilities fail to develop a sense of self-direction and self-efficacy" (1996, p.312).

The exercise of self-determination by individuals is a pattern of action, action freely taken with the intention and the expectation of producing an outcome. To the extent that use of technology provides a context in which this pattern can be experienced and assimilated, then it becomes not only an arena for the exercise of self-determination, but a context to foster the development of the personal self-attribution of efficacy, a prerequisite to a natural expression of self-determination.

Survey data from several sources validate this connection between technology use, efficacy, and self-determination. A recent research report from the multi-year Pew Internet & American Life Project based on interviews of over 3,500 people (with and without disabilities) concluded that “a person’s sense of efficacy can make a difference in her decision to go online or not.” (Lenhart, 2003, p.28) Interestingly, while this formulation suggests that the sense of efficacy precedes the act of going online, Lenhart finally concludes:

While it is not possible to assert causality definitively, it seems reasonable that those who have convenient access to a great deal of information and those who have multiple ways to communicate with others would feel more in control of their lives. (p.28)

The UIC NRTC Self-Determination Project Web Survey, currently in progress, has produced preliminary data that reveal a parallel correlation. Respondents reporting more self-determination in their lives report using the Internet more often compared to those who describe themselves as having less self-determination in their lives. Consistent with our proposed model of self-determination and technology use, the inference that those respondents are actually *exercising* self-determination via their technology use is borne out by the preliminary data showing that those reporting more self-determination were more likely to do work, look for local/state/federal government information, to purchase a product, or do word processing. In other words, they are conducting

activities that have meaningful consequences and integrate them as active agents in the life of the community.

## **Resources for Enhancing Awareness, Choice, and Efficacy**

### ***Generic Resources***

The Internet has become a household fixture for most Americans, with penetration hovering at about 60% for the last few years (Lenhart, 2003).

Every day people seek information, communicate, and conduct business across the spectrum of life management areas. We use the technology for employment, health, legal and financial matters, housing, transportation, travel and recreation, news and community affairs, and more. Advancing our aim of encouraging broader use of the technology as a tool to enhance self-determination, we explore here selected technology resources – both generic and those more germane to the needs and aspirations of mental health consumers.

General Internet guidebooks support both novice and advanced users in getting started and applying the tools for specific purposes. These guidebooks conform with our operational self-determination model in that they provide information about the range of resources and services available (awareness), they help consumers evaluate the choices available both in terms of quality and reliability as well as in measuring the degree to which any particular site fits the individual user's needs and purposes (facilitating a competent choice), and finally they lead



to mastery and efficacy through instruction in the “how-to’s” of exercising the decision to go ahead and access/use one’s chosen Internet resources.

A recent trip to a bookstore yielded several recommendable publications – although surprisingly not as many for the new user as expected. This is one area in which it may be worthwhile to invest in a book of one’s own, in part because the pace of technology and Internet development is so great that one must seek out the freshest, most up-to-date materials to get the best advice, and for newcomers it may be reassuring to have a reliable reference at hand that does not depend on computer competence for access.

A well-sequenced and highly functional basic handbook is *Using the Internet*, by Matt Lake, (Barnes & Noble Basics™, 2003). A paperback, it retails for about ten dollars. The key to this resource is that it observes the old “KISS” principle, keeping it simple for the person getting into the water for the first time. This might be a useful text for an introductory workshop for consumers at a clubhouse, inasmuch as it guides without going into technical depth or complexity. Therefore, it is not intimidating, overwhelming, or confusing with more nuances than novices can assimilate. For example, the section on search engines is but two pages. As such, on the other hand, it lends itself to a situation in which peer or staff support is available when desired.

In this connection, it is relevant momentarily to jump forward in our agenda to note that one of the key barriers to Internet use reported by mental health consumers and by people with disabilities generally is the perception that computers and the Internet are too confusing and too hard to learn to use. The UIC Web Survey earlier described asked non-users why they were not online, and nearly a third of them responded that this perception of difficulty was their primary reason – by far the most frequently cited reason among the eight closed code options and “other.” The above-cited Pew research found that 21% of non-users with self-reported disabilities had the perception that the Internet is confusing and hard to use (Lenhart, 2003, p. 31). Only nine percent of “non-disabled people” in the Pew study cited perceived difficulty as a barrier to using the Internet.

These survey findings strongly suggest that these perceptions, along with factors such as convenience, affordability, and privacy of access, likely underlie the well-documented digital divide. The same Pew study found a significant divide between people with disabilities, 38% of whom use the Internet, and all Americans, 58% of whom use the Internet (p.30). Given such findings, we would expect that the availability of supports that incorporate resources such as guidebooks are potentially effective strategies for those consumers who do have an interest in using technology but are not currently doing so.

Now, for users who have already mastered basic cyber-mechanics enough to have made the connection, other references offer guidance in taking the best advantage of it while avoiding its pitfalls. Thousands of sites are listed in directory format, cross indexed, and annotated in paperback guides such as Joe Kraynak's *Best of the Internet* (QUE, 2003). In most categories, one "Best" site is recommended, and sites that offer products or services for purchase are so marked. Categories run the full gamut from social services and health/mental health resources to sites for planning one's next trip to Chicago or for finding a romantic partner. Publishers of such guides say they check the listed sites to insure they are active and have the content described. However, new sites are born, old sites become defunct regularly, so current references are imperative.

### ***Resources of special interest to mental health consumers***

We look with a finer focus now in surveying selected technology resources that are contributing to greater efficacy in various spheres of life management for people with mental health difficulties. This survey primarily samples resources specific to mental health and employment – two areas of great interest to mental health consumers, if we rely on the previously cited early UIC NRTC Web Survey data. In that survey, consumer respondents who use the Internet say they are likely to do work and look for local/state/federal government information. Also, six out of seven non-user respondents who said they are interested in becoming users cited employment-related purposes, and seven out of ten said they would search for information on mental health diagnoses, treatments, and medications.

A substantial number of Americans are accessing mental health information on the Internet. A recent Harris poll concluded that 60,000,000 Americans searched for health information on the Internet in 2002, and of that number 40 percent were seeking information on mental health (APA PsychNET®, 2003). We can not know how many were in fact mental health consumers, but we can certainly see that seeking such information on the Internet has become a mainstream activity.

Recall the scenario that opened this paper – the staff training session that turned to an energetic discussion of depression. Participants wanted information on how to respond, how to determine the existence and severity of clinically significant depression, and how to advise their customers. I shared with them my own personal experiences with depression to convey the serious emotional and functional impact it can have, and as an example of the symptom profile that often is the signature of depression. Frankly, it was evident that some attached a stigma to psychiatric problems, so I also wanted to demonstrate that a person they saw as competent and functional – i.e., me – could experience serious and challenging psychoemotional problems at times in his life. It is noteworthy that my sharing led several participants to offer their own experiences for discussion.

However instructive the example of one person's experience, the class needed comprehensive and systematic reference points for helping customers to assess the problems they were reporting as well as to provide a set of local mental health resources to recommend to customers who want to pursue evaluation and

treatment services. To that end, I conducted a Google search on the phrase “symptoms of depression” and found that about 61,000 web sites turned up with that phrase in their site contents. What was the first site listed in my search results on “symptoms of depression?” It was SymptomsofDepression.com!

The SymptomsofDepression.com site yielded a succinct page and-a-half on identifying symptoms of depression, along with numerous links to other resources. Given that almost all the customers served by the staff I train are women, I also downloaded an in-depth 11-page document from the National Institute of Mental Health, “Depression: What Every Woman Should Know” (NIMH, 2000). Finally, I consulted the web site of the Mental Health Association of Southeastern Pennsylvania, [www.mhasp.org](http://www.mhasp.org), and was able to download an up-to-date listing of community mental health centers, referral centers for private licensed practitioners, and a listing of privately available services offered for a fee based on income, such as university-affiliated clinics.

Finding and gathering all this information into packets for my class took an hour or two of my time. My methods were basic and required no great sophistication as a user of the technology.

### ***Selected Mental Health-Related Resources***

As noted, there are many more mental health-related resources on the Internet than one person could ever take advantage of. Listed in this section are selected examples of sites that have reliable and useful information as of October, 2003.

#### **National Institute of Mental Health / [www.nimh.nih.gov](http://www.nimh.nih.gov)**

This is a major gateway as a link to many research and information sources as well as a offering a wealth of resources published by NIH.

#### **National Alliance for the Mentally Ill / [www.nami.org](http://www.nami.org)**

NAMI is a support and advocacy organization of consumers, families and friends of people with severe mental illness, with 1,200+ state and local affiliates.

#### **National Mental Health Association / [www.nmha.org](http://www.nmha.org)**

An association that works with 340 affiliates to promote mental health through advocacy, education, research, and services.

#### **Resource Center to Address Discrimination and Stigma Associated with Mental Illness / [www.adscenter.org](http://www.adscenter.org)**

The Resource Center to Address Discrimination and Stigma Associated with Mental Illness (ADS Center) was born out of a need to assist individuals, the public, state and local governments, and private and non-profit organizations in the design, implementation and operation of programs to reduce discrimination

and stigma associated with mental illnesses. The goal of the ADS Center, which is a project of the Center for Mental Health Services (CMHS) of the Substance Abuse and Mental Health Services Administration (SAMHSA), is to enhance mental health consumer independence and community participation by ensuring that people have the information they need to counter discrimination and stigma.

For individuals, one of the ADS Center's most valuable forms of direct assistance is its annotated listing of Internet web sites for information and contacts related to ten defined spheres in which discrimination and stigma are active factors. The ten categories of web site resources are:

- Employment
- Housing
- Health Care and Insurance
- Culture and Gender
- Children
- Older Adults
- Media and Entertainment Industry
- Language and Terminology
- Policy and Legislation
- Effects of Stigma and Discrimination.

On the topic of Health Care and Insurance, as an example, 21 sites are broken out across three types of resources available at the respective sites: Brochures and Fact Sheets; Books, Articles and Research; and Resource Organizations. Each of the listed sites has been visited and reviewed by Center staff and each listing includes a narrative description of key contents of special value to users.

## **National Mental Health Consumers' Self-Help Clearinghouse**

[www.mhselfhelp.org](http://www.mhselfhelp.org)

Especially informative site for identifying and networking with groups and individuals active in promoting advocacy and recovery efforts, and for researching and identifying quality mental health services, with particular emphasis on peer-run services. The Clearinghouse offers a valuable Technical Assistance Guide, ***Advocacy and Recovery Using the Internet.***

## **UIC National Research and Training Center / [www.psych.uic.edu/uicnrtc](http://www.psych.uic.edu/uicnrtc)**

The National Research and Training Center on Psychiatric Disability conducts research, training, technical assistance and dissemination activities designed to promote self-determination among people with psychiatric disabilities. The overarching premise of the Center's activities is that persons with psychiatric disabilities have the right to maximal independence, which grows out of making choices regarding the decisions that affect their lives. The Self-Determination Workshop Series is a UIC NRTC program. One of these workshops, a webcast devoted to using the Internet for advocacy and for job search, is available for download as an archive on the site. The NRTC offers a "starting-from-scratch" guidebook for gaining access to the Internet and finding resources,

***NAVIGATING THE INFORMATION SUPERHIGHWAY: INCREASING INTERNET KNOWLEDGE AND USE AMONG MENTAL HEALTH STAKEHOLDERS.***



**International Society for Mental Health Online / [www.ismho.org](http://www.ismho.org)**

As stated on the site, “The International Society for Mental Health Online (ISMHO) was formed in 1997 to promote the understanding, use, and development of online communication, information and technology for the international mental health community. ISMHO is a nonprofit corporation.”

The site highlights emerging literature via direct links to articles, and a special focus of its resources is the online provision of services.

**American Psychological Association / [www.apa.org](http://www.apa.org)**

In addition to featuring activities and publications of the APA as a professional organization, several consumer-oriented components of the site make it particularly valuable for the promotion of self-determination. The site’s “Help Center” is a user-friendly resource that is organized by questions that lay people with mental health-related concerns would ask.

Another apa.org component, at [helping.apa.org](http://helping.apa.org), offers downloads of consumer-oriented brochures and information. Highly recommended here is *dotCOMSENSE: Common Sense Ways to Protect Your Privacy and Assess Online Mental Health Information*. This resource guides online users with detailed, practical measures and links to specialized sites for such further resources as “cookie management software.” Its pages cover core topics for users’ self-protection: Privacy, What are Cookies and How Do I Block Them?, Watch for Commercial Influences, Exercise Caution, and Resources, including

links to government and private organizations that help consumers protect their privacy and uncover untrustworthy dealings. *The Road to Resilience* is another printable publication that addresses psychoemotional resilience as a key factor in mental health and features grounded, practical approaches to building and maintaining resilience.

### ***Selected Employment-Related Resources***

The Internet is rife with employment-related resources, both general and those targeted to serve people with disabilities. The range of these resources is sampled and evaluated in the above-referenced UIC NRTC Self-Determination Workshop Series Live Webcast, October 22, 2002, available as an archive for viewing. There are 40+ pages of downloadable print exhibits and resource listings associated with the employment-oriented segment of that webcast, titled “The Electronic Career Stairway: Steps to Finding the Right Work via the Internet” (Dansky, 2002). In this section selected employment resources of special interest to consumers are reviewed.

### **Ability Forum / [www.abilityforum.com](http://www.abilityforum.com)**

A diverse gateway to many Internet resources and services. Main menu offers “**Job Center**,” “**Resource Center**,” and “**Town Square**.” The job listing database numbers over 10,000 job postings. Other features of the site include pages on Ticket To Work, Assistive Devices, Educational Programs, and a social meeting place, called Meeting Place.

**Job Access / [www.jobaccess.org](http://www.jobaccess.org)**

Assists job seekers looking for work with businesses, government, or nonprofits.

**Job Accommodation Network (JAN) / [www.janweb.icdi.wvu.edu](http://www.janweb.icdi.wvu.edu)**

JAN is a free service of the U.S. Dept. of Labor Office of Disability Employment Policy. JAN provides information and consultation on job accommodations, the ADA, and the employability of people with disabilities. JAN consultants respond to online user questions concerning employment accommodations for individuals.

The **Small Business and Self-Employment Service (SBSES)** is a program of the Job Accommodation Network which provides comprehensive information, counseling, and referrals about self-employment and small business ownership opportunities for people with disabilities. The SBSES Web site provides an extensive database of resources addressing both disability-related and self-employment issues. Those who regularly use SBSES services include:

- Individuals with disabilities who are interested in exploring self-employment and small business development options.
- Service providers working with consumers who are interested in exploring self-employment.
- Friends and family members of someone who is interested in becoming self-employed.

SBSES consultants assist consumers in exploring self-employment options by providing consultation and resources related to business planning, marketing research, potential funding sources, Social Security work incentives, credit repair strategies, microenterprise development, and many other issues.

**National Center on Workforce and Disability/Adult (NCWD/A) /**

[www.onestops.info](http://www.onestops.info)

Rich source of, and gateway to, information and resources on best practices, guidelines on needs and rights of consumer/survivors seeking work, disability-related policies and laws, ADA, Ticket To Work, etc. The NCDW/A is based at the Institute for Community Inclusion at the University of Massachusetts Boston.

**State Vocational Rehabilitation Agencies / [www.parc.org/svrp.html](http://www.parc.org/svrp.html)**

This Pennsylvania Rehabilitation Council web site links to all state VR agencies.

**Ticket to Work Web site from SSA / [www.ssa.gov/work/Ticket/ticket\\_info.html](http://www.ssa.gov/work/Ticket/ticket_info.html)**

This site provides information of interest to beneficiaries who want to learn about the ins and outs of the Ticket To Work program for supporting return to work.

**Challenges, Barriers and Pitfalls**

Several of the challenges, barriers and pitfalls encountered in consumers' use or prospective use of information and communication technology have been cited in the course of this review. One is the digital divide between the disabled and non-disabled population and its causes. Other references have alluded to two major

concerns that have particular salience for mental health consumers, namely privacy issues and the trustworthiness of online information and online interactions, whether of a business, professional, or social nature. These legitimate concerns need to be brought to light, and it should be recognized that there are strategies for minimizing their causes and the perceived and real risks.

A key phenomenon widely addressed in the literature is the digital divide. In the discussion of resources above, several surveys suggested that consumers who would like to use the Internet avoid doing so because they perceive it as too confusing and hard to use. The inference drawn by Lenhart from the Pew Internet & American Life research is that many non-users become new users when they attend unintimidating classes that provide personal attention and are tailored to their needs, and when they had more affordable access to computers and the Internet.

In the case of the community experience of mental health consumers, all of these conditions might most easily be met in the context of an accommodating psychosocial rehabilitation program. However, a survey conducted at a national psychosocial rehabilitation conference in 2000 revealed that consumer participants in three-quarters of the programs represented in the survey did not typically have access to computers at the program site (Dansky, Granger, Bradley and Jonikas, 2001). While libraries and other public venues may afford free access, they also may discourage consumers because they are public

venues. As the one place outside the home that honors and supports consumers and their aspirations for full community participation, these programs need to be encouraged and guided in engaging consumers with online resources.

Privacy is a major concern for people who may have experienced intrusions on their privacy as well as legitimate concerns about stigmatization. However, one has a choice of turning a concern into an impenetrable barrier or of approaching with due caution and armed with prudent and effective strategies for self-protection. For those who would make the latter choice, the APA publication dotCOMSENSE referenced earlier guides the user in assessing the privacy protections of web sites and in actually regulating the exchange of information (in the form of cookies) so as to avoid leaving identifying information with the site.

There are various strategies for hiding one's identity online. A review of strategies for keeping one's identity to oneself while online appears in *PC Magazine* (Canter, 2003). These strategies range from easy-to-implement no-cost ways of hiding one's identity – e.g., obtain a Web e-mail address from Yahoo! for sending e-mails – to anonymous remailers that involve more sophisticated knowledge but are more difficult to penetrate, to much more technically demanding encrypted remailers that are most secure from penetration.

Finally, the Identity Theft Resource Center at [www.idtheftcenter.org](http://www.idtheftcenter.org) is a nonprofit organization online “dedicated to developing and implementing a comprehensive

program against identity theft. Users will find updated information about schemes and scams and advice on the best protections and practices for avoiding – and/or responding to – identity theft.

The issue of trustworthiness of online information and interactions rightly looms large. Again, dotCOMSENSE at the APA web site had a set of guidelines for evaluating credibility and quality of a site's information. There are hoaxes and scams, and there are ways of recognizing them. Brad Berens' "Can You Believe a Web Site?" (<http://www.earthlink.net/elink/issue29/focus.html>) and the unattributed "The Truth About Email Hoaxes" ([http://www.earthlink.net/elink/cmp/focus/focus\\_100702.html](http://www.earthlink.net/elink/cmp/focus/focus_100702.html)) advise users on the signs of illegitimate sites and communications. In this connection, one often-referenced and highly regarded web site that merits special mention is snopes.com, at [www.snopes.com](http://www.snopes.com), also known as the Urban Legends Reference Pages. It is an online credibility report maintained by the husband and wife team of Barbara and David Mikkelson.

## **Conclusion**

Our aim has been to make the case that technology is a valuable and powerful tool for promoting individuals' self-determination. Our model was drawn through general and specific instances to show operationally how, at least in theory, certain types of Internet use can become the scaffolding by which consumers might experience and assimilate a pattern of awareness, choice and efficacy.

We asserted that there is too much value to be gained from consumers' use of technology to be deterred by the challenges, barriers and pitfalls associated with that use. Most of this review has been devoted to demonstrating that value, in the belief that consumers must first see and be drawn to that value before they make the adaptation to become technology users. There are solutions to issues of access and adoption. There are effective ways of protecting privacy and testing trustworthiness, ways of recognizing and avoiding pitfalls on the Internet.

In asserting the role of the Internet in promoting consumers' self-determination and proposing a model to show operationally how that comes about, we know that we still lack empirical validation. The survey research now being undertaken is the first phase of looking at patterns and consequences of the relationship between consumers and this technology. Model--testing research lies in the future.



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# Self-Determination in Mental Health Recovery: Taking Back Our Lives

*By Mary Ellen Copeland*

The most important aspect of mental health recovery for me personally is self-determination. My connection with people in the system and in recovery has convinced me that the same is true for others. In this paper I will discuss both my personal perspectives and the perspectives of others on this important topic based on many years of experience as a person, a user of mental health services, a researcher and a teacher. It will include: 1) my personal story of taking back control of my life; 2) breaking down barriers to self-determination; 3) values and ethics that support self-determination; and 4) self-determination facilitators: WRAP and Peer Support.

## **My Personal Story**

For many years I was dependent on the mental health system and other “supporters’ for my well-being and to make major decisions about the important aspects of my life. I depended on this system to provide for all of my needs including food, shelter, clothing, treatment and medications. As time went on, my level of dependence increased. And through that time the circumstances of my life deteriorated. After having gotten a good education, raised a family and had a successful career, I found myself, in my mid-forties, living in a housing complex

for the elderly, on social security disability, filled with shame and despair, my records declaring that I was permanently disabled.

I remember the day all of that changed. As I was leaving my psychiatrist's office with the prescriptions for a new "soup" of medications, he said to me, "Mary Ellen, if this doesn't work, we'll try ECT." My mother had ECT many years ago, and after that she couldn't remember the time when my siblings and I were growing up. It was a huge loss to her. I was clear ECT was not a road I wanted to take. I decided that day to take back control of my life—to determine my own future. And that decision has led me on an incredible journey.

My first step was to find out how others -- who, like myself, had multiple psychiatric labels -- cope with these symptoms or difficulties as I like to call them, on a day-to-day basis. So I asked my psychiatrist. He said he would get me that information for the next time. But when, at the next appointment I asked him for that information, he told me there wasn't any information like that. There was only information on medication, hospitalization and day treatment programs.

So I developed a scheme that some people might call "grandiose", particularly for a person with a history of extreme mania and depression. I would interview people who have had these symptoms, find out how they cope, and use those skills and strategies to recover and get on with my life. In the fifteen year since I decided to take back my life, I have talked to thousand of people all over the

world. I have compiled the information they have shared with me into a mental health recovery program, have written 12 published books (distribution in the hundreds of thousands), teach others this information, and now am focusing on teaching others how to teach this information.

The most important concept that has come out of all of this—absolutely key to the recovery journey—is self-determination. Some people talk about a defining moment—that moment when they knew they had to take back control over their lives. Others describe a gradual process, an awakening. But without self-determination, people stagnate. They become more and more dependent, and more and more convinced that they will never fulfill their life dreams and goals.

It is exciting to me that mental health agencies and organizations are now recognizing the importance of self-determination—some with vigor and some more reluctantly-- and are moving to rebuild the system to reflect this change.

### **Breaking Down Barriers to Self-Determination**

There are many assumptions about “mental illness” and mental health that must change, and are changing, that will facilitate the personal process of self-determination and taking back our lives.

When I first decided to reach out for help to deal with the difficult feelings I had been having all my life, I went through a lengthy questioning process

(assessment) that had little or nothing to do with the way I was feeling. I was given a diagnosis, told what that diagnosis would mean in terms of what I could expect in my life, and given medications that I was told I must take, probably for the rest of my life. Little attention was paid to my “out of control” lifestyle, my abusive relationship and my history of childhood sexual and emotional abuse and trauma. My definition of myself changed in a very short time from person, mother, teacher, artist, writer and naturalist to “mental patient,” a person who needed others to take care of me and make decisions for me. My power was taken away and I felt different from others and alone. Unfortunately, this is a common scenario that many still experience.

What would an alternative view look like that would allow for a different outcome—an outcome that would help me get my life back, change and grow, and work toward my own goals and priorities? As before, I am dealing with difficult feelings and behaviors. I reach out for help. The person or people I reach out to assume that if I am feeling this badly, something bad has happened to me. They want to know about these things. They want to know how they can help. I am listened to. I am supported. I feel validated and safe. I am connected with peers. Together we work on seeing our feelings and behaviors in new ways and work together to find new ways of responding that foster wellness and recovery. In this trauma informed scenario I keep my personhood. I keep control of my own life. My difficulties are seen as normal human responses to bad things that have

happened to me, either recently or a long time ago. I can move forward, creating change based on my needs, dreams and goals.

For many years it has been assumed that those of us who experience psychiatric symptoms can never get well, and often get worse over time. Now we know that many, many of us have become empowered, gotten well, stayed well for long periods of time, have determined their own goals and priorities and are working toward meeting them.

Another common misperception was that those of us who experience psychiatric symptoms need to be controlled and “taken care of,” that we cannot control or take care of ourselves. Now we know that those of us who experience psychiatric symptoms can control ourselves, take care of ourselves and make choices about our own treatment and our own life. Empowerment and choice hasten recovery rather than interfere with it.

Some people have assumed that that because we have difficult times, we can't learn, and we can't make decisions, that only highly trained medical professionals understand these symptoms and can make decisions about our lives. We have always known that we can learn, and now we use our ability to learn to make good decisions for ourselves—decisions based on our own personal values and priorities—about our treatment and other aspects of our lives. Others also thought that those of us who experience psychiatric symptoms

could not advocate for ourselves, that we need others to decide for us what would be best for us, and then to advocate for us. Now we know that we can almost always advocate for ourselves. If we are having a very difficult time, we can ask for the help of family and friends who know our preferences.

Those of us who experience these symptoms were told that we should not associate with others who experience similar symptoms. Now we know that others who have experienced psychiatric symptoms can often be the best of supporters. We can understand each other and support each other in ways that are really helpful. We can “be” with our discomfort rather than needing to “fix” it immediately, and support each other through recovery. We can challenge each other to take risks and create change that would be difficult to accomplish alone.

The idea that when we are having a difficult time we need to be forcefully controlled, confined and subdued has been a widespread belief through the system for a long time. This kind of “treatment” which many of us referred to as “punishment” did not help and often made us feel worse, traumatizing us again and again, and making it much more difficult to get well. Now we know that when we are having a difficult time, there are many things we can do to help ourselves feel better. We have developed documents that instruct others on how to take care of us in ways that are really helpful when we need that help. We have advocated for the development of safe places where we are listened to, validated and supported by others who understand what we are experiencing.

In the past, it was thought that we couldn't do anything to help ourselves. Others failed to recognize our strengths and instead saw only what they considered to be our deficits. Now we are recognizing our own strengths and using those strengths to prevent and relieve symptoms and to keep ourselves well.

### **Values and Ethics that Support Self-Determination**

In order to support mental health recovery and self-determination, the system must be guided by redefined values and ethics. Through my years in this field, I have become aware of some these values and ethics. When I think the list is final, another important concept is brought to my attention that belongs on the list. Therefore, the list I am sharing with you is a "work in progress."

For these values and ethics to become entrenched in the system so we can take back our lives, each of us has to speak out whenever necessary.

The first value that literally "jumped off the page" at me as I was compiling information from my first study was *hope*. For years people had been told that they would never recover, never meet their life goals and dreams. Every time they heard this, usually from a well-meaning care provider, they felt worse and worse. Only when they began to hear messages of hope, and that others were recovering and doing the things they want to do, did they begin to realize that the same was possible for them.



Second only to hope was self-determination, called by several different names-- personal responsibility, empowerment, self advocacy and self efficacy--but meaning the same thing—and absolutely essential to taking back control over our lives.

Other values and ethics that support self-determination and recovery, values and ethics that the system and each of us must personally embrace, include:

- treating each other as equals, with dignity, compassion, mutual respect and high regard.
- unconditional acceptance of each person as they are, unique, special individuals, including acceptance of diversity with relation to cultural, ethnic, religious, racial, gender, age, disability and sexual preference issues.
- avoidance of judgments, predictions, put downs, labels, blaming and shaming.
- “no-limits” thinking (the word prognosis belongs in the circular file)
- validation of personal experience.
- choices and options, not final answers.
- voluntary participation.
- each person being recognized as the expert on themselves and having a sense of their own personal value.
- use of common rather than clinical, medical and diagnostic language.

- focus on working together to increase mutual understanding and promote wellness.
- concentration on strengths and away from perceived deficits.
- basic needs like housing, food, money are taken care of when we can't meet these needs ourselves, and as we are working on our recovery.

Only with these values and ethics, can we overcome the powerlessness, fear, insecurity, sadness, isolation, worry and low self esteem, as well as the internalized discrimination, prejudice, and/or stigma which so easily become the trademark for those of us who experience these difficult symptoms.

## **Self-Determination Facilitators**

### **1. Wellness Recovery Action Planning**

One of the most profound recovery tools that I have discovered, one that is totally founded in the concept of self-determination, is the Wellness Recovery Action Plan. Back in 1997, I was working with a group of 30 people, people who had been struggling for years with various psychiatric symptoms, teaching them the recovery skills and strategies I had been learning. They found this to be somewhat helpful. However, when a woman said that she had not idea how to incorporate these tools and strategies into her life, we began working together to

develop a system to do that. And that system, now being used around the world, is WRAP.

WRAP is a plan or a process for identifying the resources that each person has available to use for their recovery, and then using those tools to develop a guide to successful living that they feel will work for them. People can develop these plans on their own, guided by the resources I have developed. However, many of them prefer to work on these plans in groups, getting ideas and feedback from others who share their experiences. Most of these groups are organized and facilitated by peers. The group process helps people move from a “learned helplessness” or “mental patient” view of themselves to seeing themselves as people with resources who can determine the course of their own lives.

WRAP development begins with building a personal Wellness Toolbox. In working on the Wellness toolbox, people come to recognize the vast resources of choices they have available for self-help and self-determination. These tools range from things like getting 8 hours of sleep every night, drinking 6-8 ounce glasses of water a day, playing with your dog, doing deep breathing exercises, avoiding sugar, and staying away from bars to spending time with peers, doing peer counseling, taking a course, joining a support group, developing leadership skills, letting go of addictions and learning new responses to troubling situations. Working together, people come up with long lists of simple, safe, effective and

often free things they can do to stay well, relieve symptoms and make their lives the way they want them to be.

This Wellness Toolbox is used to develop a personal plan that includes identifying the things to do every day to stay as well as possible, upsetting things that happen that could be “triggers”, early warning signs and signs that things have gotten much worse and developing plans using their own resources that will help them to feel better in each of these circumstances. This simple planning process has allowed numerous people to gradually or quickly take back control of their lives.

WRAP also includes a crisis plan that tells others what they want them to do to help when things become really difficult for them. The post crisis plan is a personally developed guide for the person to use when they are getting over a difficult time.

One of the key barriers to WRAP being used as it was designed and intended is that it often gets co-opted and redesigned by a program or an agency. In this process the self-determination aspects are often obliterated. Attending WRAP classes is mandated. People are told how many items they need on each list and what to put on the list. They are told they must complete their WRAP and when it needs to be completed. The care provider may insist on storing the WRAP in their office between sessions and even after it is completed, or having

a copy of it in their file. They may also insist on monitoring the person's progress, whether they are doing the things on their daily maintenance list every day, whether they used the right tools when they were triggered and so on.

It is essential that WRAP remain a self-determination tool. As such, WRAP is only WRAP when the following guidelines are adhered to:

*There is only one person who can write your WRAP—YOU.*

*You, and only you, decide:*

*If you want to write one,*

*How much time it takes you to do it*

*When you want to do it*

*What you want and don't want in it*

*Which parts you want to do*

*Who you want, if anyone, to help you with it*

*How you use it*

*Who you show it to*

*Where you keep it*

*Who, if anyone, has copies of your crisis plan*

**Copeland, M. *Mental Health Recovery and WRAP Facilitator's***

***Manual. Brattleboro, VT revised, 2002***

For a person who has been in the system a long time, WRAP is often a person's first introduction to the idea that their ideas and views have value, and that

they can make their own decisions and move on with their recovery. It can be the initial step in the recovery process.

## **2. Peer Support**

Taking back control of your own life is a difficult task. It is even more difficult if you are trying to do it alone. Peer support programs that are developed by and for peers, and that are peer operated and offered instead of or in addition to traditional services can meet this need. They offer people the opportunity to get together with others who have had similar experiences, to support each other in taking back control of our lives, and to learn new ways of doing and being that replace old patterns and responses that perpetuated or worsened difficult times. In addition, they often offer leadership opportunities, education, training and job opportunities that build self-esteem and open the door to personal development and an improved quality of life.

However, if careful attention is not paid, these programs can easily revert back to the hierarchical systems that take away personal power and control. They can become just a new name for doing things the same old way. On going program evaluation and refinement by program participants is assessment is essential to insuring that these programs work toward their vision and support people in taking back control of their lives.

## **In closing**

In the years since I have been working closely with the mental health system, I have seen phenomenal movement toward a system that is truly focused on recovery and self-determination. Thankfully we are light years away from the time in the late forties and early fifties when my mother spent 8 years confined and controlled in a horrific institution. On the one hand I am convinced that we have come so far and so many people are empowered, that we can never return to those infamous days. On the other hand, I know that we all must be vigilant, especially in these times, to retain the gains we have made and continue our progress.

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# Early Findings of the University of Illinois at Chicago National Research and Training Center's Web-Based Survey on Consumer Self-Determination and Technology

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## Introduction

The purpose of the project described in this paper was to conduct an Internet survey of a large number of mental health consumers about issues related to self-determination and technology. Participants were asked to describe their personal feelings and experiences of self-determination, opinions about the mental health service delivery system, and use of information technology. The survey was created by the University of Illinois at Chicago (UIC) National Research and Training Center's (NRTC) Self-Determination and Technology Workgroup. This participatory action workgroup is comprised of consumers, advocates, and researchers interested in the application of information technology to mental health issues.

Self-determination refers to the right of individuals to have full power over their own lives, encompassing concepts that are central to existence in a democratic society, including freedom of choice, civil rights, independence, and self-direction (Cook & Jonikas, 2002). In the United States today, individuals with serious mental health problems experience minimal self-determination given society's failure to provide them with adequate, recovery-oriented services or choices in how to use available services

(Ahern & Fisher, 1999; Lamb, 1994; Manderscheid, Henderson, et al., 1998). For those who do seek help, services often fall far short of those considered even minimally adequate for clinical care, rehabilitation, and recovery (Lehman, Steinwachs et al., 1998). This has created a need for consumers to be able to access information about desired services and supports, as well as the latest scientific breakthroughs in the causes and treatments of mental illness.

In society in general, and in the field of rehabilitation in particular, new information is being distributed at an unprecedented rate (Barrett, 1994), which is increasing exponentially due to advances in information technology (IT), particularly use of the Internet. This has led to concerns about maximizing access to IT by a wide variety of stakeholders, especially consumers of rehabilitation services (Fullmer & Mujumder, 1991). Similarly, there is growing recognition in disability disciplines that the gap between the development of knowledge and knowledge application can impede both consumers' personal progress as well as innovation in service settings and systems (Zeren et al., 1999).

Many individuals and organizations, particularly those attuned to mental health consumer and family issues, cannot afford even minimal funds to bring in experts to conduct training or pay for technical assistance and consultation. This suggests that the use of technology, such as personal computers and electronic networking, may serve as a cost effective way to distribute information to vast underserved audiences. However, many people lack access to these new technologies, leading to the much-discussed "digital divide." According to the U.S. Department of Commerce, households with incomes above \$75,000 are 20 times more likely to have access to the Internet

than lower-income households (Foxhall, 2000). Differences in literacy rates, inadequate computer education, lack of high-speed equipment, and scarcity of culturally relevant information on the World Wide Web also impede the appeal and utility of technology for many communities.

Because of these issues, the NRTC survey focused on the level of consumers' access to and use of information technology, specifically the Internet, as well as how this was related to self-determination. The audience for the survey results was conceptualized as including consumers/survivors, policy makers, families, advocates, researchers, service providers, and system administrators.

### Methodology

A convenience sample was obtained through an announcement posted to a number of mental health listservs and Websites, sent to members of the NRTC mailing list, and advertised in newsletters targeted to consumers and other mental health stakeholders. This announcement explained the purpose of the survey, described eligible respondents, and directed interested participants to a secure Web address where they could complete the survey online with complete anonymity. Contact information for UIC NRTC project staff was provided for the use of respondents with questions or those having difficulty completing the survey.

The survey Website could be visited by anyone having access to the Internet. At the Website, participants were presented with a series of survey question that took approximately ten to twenty minutes to complete, depending on the "skip pattern" created by replies to certain questions. As surveys were completed and submitted, each respondent's information was automatically entered into a secure and protected

database, accessible only to the UIC research staff. The survey Web page and database were hosted with WebSurveyor Corporation, a private, for-profit research firm. All transmitted data were encoded using Secure Sockets Layer encryption. No Internet Protocol (IP) addresses linked to specific hardware used to complete the survey, nor any other identifying information about the respondents were collected.

Individuals eligible to complete the survey were those who self-identified as having experienced mental health difficulties, those reporting a diagnosis of mental illness or use of psychotropic medication, and/or those who said they had been hospitalized for mental health reasons. Exclusion criteria included individuals who could not read English, those without access to the Internet, individuals who did not self-identify as mental health consumers, and minors (given human subjects requirements of parental consent, all information from individuals indicating that they were less than 18 years of age was excluded). The preliminary posting period occurred from July through September of 2003.

The survey was comprised of three basic sections. The first section elicited respondents' feelings about the degree of self-determination in their lives by asking consumers: 1) an open-ended question about what fostered and impeded their own self-determination; 2) closed-ended questions about different aspects of self determination such as control over finances, residential status, and treatment; 3) for a rating of the degree of self-determination in their lives on a scale from 0 to 10; and 4) about their level of self-determination as it related to receiving mental health services. Those not receiving services responded to a separate set of questions asking why this was so. The second section of the survey asked about respondents' access, use, and

barriers to use of information technology. The third section asked about respondents' demographics (including gender, age, education, and racial/ethnic background), as well as features of their clinical history (such as diagnosis, prior psychiatric hospitalizations, and whether they were receiving mental health services).

## Results

Characteristics of the respondents. A total of 619 individual respondents completed the survey. The large majority of survey respondents either reported a specific diagnosis (97%), said they were currently taking psychotropic medication(s) (97%), and/or had experienced a mental health hospitalization (88%). Most respondents (88%) were Caucasian, with smaller proportions of African Americans (3%), those with mixed ethnicity (3%), and 2% Hispanic/Latinos (2%). Close to three-quarters (72%) were female, and their average age was 45 years (with a range from 18-71 years). Most were single, with only 38% reporting being married or cohabiting. The large majority (90%) had completed high school or a GED. Half (51%) were employed (35% full-time and 16% part-time). A third (33%) had household incomes less than \$15,000/year, while only 15% reported household incomes greater than \$70,000/year. Close to two tenths (38%) lived in urban areas or suburbs (38%), and a quarter (24%) resided in rural communities. In addition to their status as individuals with mental health problems, 46% reported that they were advocates, 44% were relatives of someone else with MH problems, 16% were program directors, 15% were service providers, 13% were students, 11% were researchers, 10% were teachers, and 15% did consulting.

Degree of personal self-determination. As defined for respondents in the survey instructions, the concept of self-determination referred to the freedom to be in charge of

one's own life including one's residence, friends, and activities. It also meant having the resources to create a good life, make responsible decisions, and choose where and how one received support and assistance for mental health problems. When asked to rate their degree of personal self-determination, 47% said they did not have enough money to live reasonably well, and 41% said they did not feel part of their community. Around a third (34%) did not feel that other people in their lives respected their beliefs and needs, 34% felt they did not have the freedom to live the way they wanted to, and 32% did not feel that their basic civil and human rights were respected. On the other hand, 82% reported having control over how their money was spent, 83% felt they had a decent and affordable place to live, 74% indicated having a choice about whether they wanted to live alone or with someone else, and 84% reported that they had the transportation they needed.

Regarding the degree of self-determination in their mental health treatment, 47% of the respondents felt they did not have a choice about the amount of mental health treatment they received, 38% said they lacked choice about the type of treatment, and 42% reported that their health care coverage did not allow them to get the treatment they felt they needed. On the other hand, 82% reported that they knew ways to manage their own emotional problems, 80% felt they had the skills to advocate for themselves, 78% reported having access to self-help or support groups, and 78% said that recovery was the focus of their mental health treatment.

Experiences with mental health service providers. A large majority of respondents (85%) reported having mental health care insurance coverage, and 83% reported currently receiving services “from a doctor, counselor, therapist, or nurse.”

Respondents receiving services were asked their opinions about the provider with whom they had the most contact. Regarding these providers, 37% felt their providers were not helping them to build a meaningful community life, 22% felt their providers failed to focus on life areas other than mental illness, 18% felt their providers failed to accept consumers' desired treatment goals and plans, and 15% felt their providers did not work in partnership with them. On the other hand, 89% of respondents felt their providers respected their life choices, 88% felt providers honored their need for autonomy, 87% felt their providers avoided use of coercion or intimidation, and 87% felt their providers honored their service choices.

Only 17% of respondents reported that they were not currently receiving services. When asked why they were not receiving services, 46% said they did not need services, 43% did not like the services they had received in the past, 37% said they did not trust service providers, 30% felt that they had recovered, and 29% said they did not have the ability to pay for services (respondents could check more than one answer to this question). Of those who were not receiving services but felt they needed them (i.e., the 54% who did not indicate that they no longer needed services), 48% said they did not trust providers or disliked past services, 31% said there were no good providers in their local areas, and 24% said they wanted to avoid past coercive, restrictive or traumatic experiences they'd had with providers.

Relationship between provider experiences and self-determination. In order to determine whether respondents' experiences with their service providers were related to their self-assessed level of self-determination, we examined zero-order relationships between these two domains. Results revealed that consumers who rated themselves

highest on self-determination were significantly more likely ( $p < .001$ ) to feel that their providers were helping them build a meaningful community life, to work with providers who respected their choices about mental health services, to work with providers who were willing to revise treatment plans and goals whenever requested, and to have access to self-help and peer support services.

Reported use of information technology. As expected, given the nature of the study as an Internet survey, the large majority of respondents (97%) said they used a computer, and 87% said they did so at home. When asked to estimate their frequency of use, most said they used the Internet 3 to 5 times a week. Of the 97% who reported that they used the Internet, the most common uses were: sending or receiving email (98%); searching for health or medical information online (97%); obtaining information about mental health issues (92%); visiting government Web sites (92%); and getting news online (92%). People who used the Internet more frequently were significantly more likely ( $p < .05$ ) to be younger, male, married, employed, a college graduate, and from higher income brackets.

Relationship between use of information technology and self-determination. Finally, we wanted to explore potential relationships between respondents' Internet use and the degree of self-determination in their lives. Respondents reporting higher levels of self-determination were significantly more likely ( $p < .001$ ) to report that they had access to a computer, and that they used the Internet more frequently. Those with higher levels of self-determination also were more likely to say they knew how to access the Internet in their local communities (for free or for a fee), and more likely to report



using the Internet to do work, look for local/state/federal government information, to purchase a product online, or do word processing ( $p < .001$ ).

### Summary and Conclusions

The results of this study revealed that survey respondents were a highly educated, primarily Caucasian, mostly female group of consumers. Their average age was in the mid-forties, most were college graduates, and most were computer owners and frequent Internet users.

The large majority of respondents were users of the formal mental health service delivery system, and many reported having access to self-help and peer support. Most were fairly satisfied with the degree of choice and respect they encountered in the mental health service system, but a notable minority reported dissatisfaction with their service providers and/or services they received.

Many consumers felt that their providers honored their life and treatment choices and that they were able to determine their own treatment goals. Fewer felt their providers were helping them create a meaningful life in the community, and that their providers focused on issues other than mental illness. Some avoided treatment because of lack of good providers in their local area or prior bad experiences with mental health treatment. There was a statistical relationship between reporting positive experiences with service providers and respondents' self-assessed degree of personal empowerment.

Many consumer Internet users reported that they sought information about mental health services, medications, and diagnoses on the Web. Many also searched for service providers on the Internet, and visited government Websites for information.

There was a statistical relationship between frequency of Internet use and self-assessed degree of personal empowerment. Frequent Internet users reported higher levels of self-determination in their lives, which may or may not have been due to use of the Internet.

Our first look at these data raises some concerns, but also offers several inspiring messages. While many respondents felt that they had control over their money, housing situation, and transportation, many also reported not having enough money to live reasonably well, and a lack of choice and control over mental health treatment choices. Many respondents did not feel a part of their communities, nor respected by others, and did not feel they had the freedom to live as they wanted to. But most reported having the skills to advocate for themselves and manage their own emotional problems, along with the belief that the major goal of their mental health treatment is recovery.

Since close to half of this group identified themselves as “advocates” in this survey, it is noteworthy that many appear to be using tools, such as the Internet, that enable individuals to advocate for themselves, as well as to organize others in groups that can advocate for each other. Compared to the “average” Internet user in the U.S., as described in the Pew Internet and American Life Tracking Surveys (March 2000 - June 2003), larger proportions of these mental health consumers used the Internet to access health and mental health information, visit a government Web site, get news, and send or receive email. This suggests cautious optimism about the ability of some consumers (admittedly those already online) to access and use the Internet to better their lives and enhance their freedom of choice. Hopefully, others will explore these

issues in subsequent surveys, so that the benefits of those and other forms of information technology can be made available to increasingly larger groups of mental health stakeholders.

### Acknowledgement

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**UIC NRTC 2003 NATIONAL  
SELF-DETERMINATION &  
PSYCHIATRIC DISABILITY CONFERENCE:**

**TRACK #2 PAPERS**

**SELF-DETERMINATION IN MENTAL HEALTH  
AND OTHER SYSTEMS**

# CONTEXTUALIZING SELF-DETERMINATION WITHIN A MENTAL HEALTH RECOVERY ORIENTED SERVICE AND SUPPORT SYSTEM

**By Steven J. Onken, Ph.D., Columbia University School of Social Work**

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## **Abstract**

There is increasing convergence of defining mental health recovery as the ongoing, interactional process/personal journey and outcome of restoring a positive sense of self and meaningful sense of belonging while actively self-managing psychiatric disorder and rebuilding a life within the community. Recovery is facilitated or impeded through the complex, synergistic and dynamic interplay of the characteristics of the individual, the characteristics of the environment and the characteristics of the exchange between the two. Primarily informed by the research and work of the *Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators*, this paper contextualizes self determination theory (i.e., competence, relatedness, autonomy) and social self-determination within this ecologically based phenomenon of mental health recovery. It highlights enhancing and hindering environmental characteristics (such as service systems) and the powerful influences of the nature of the exchange between the

individual and his or her environment (such as the process and role of choice).

## **Introduction**

At the prodding of the mental health consumer/survivor movement, more and more mental health systems and providers are acknowledging the notion of mental health recovery. Such recovery can best be understood through the lived experience of persons with psychiatric disabilities, and through understanding the roles, both positive and negative, that forces and factors play in recovery. Inherent in the notion of recovery is an emphasis on self-determination, which in turn shapes and is shaped by these forces and factors as well. This paper contextualizes self determination theory (i.e., competence, relatedness, autonomy) and social self-determination within the ecologically based phenomenon of mental health recovery. It highlights enhancing and hindering environmental characteristics and the powerful influences of the nature of the exchange between the individual and his or her environment has on shaping self-determination.

## **Conceptualizing Recovery**

An ecologically based conceptual paradigm for organizing and interpreting the phenomenon of mental health recovery is emerging across research findings. There is increasing convergence of defining recovery as the ongoing, interactional process/personal journey and outcome of restoring a positive sense of self and meaningful sense of belonging while actively self-managing psychiatric disorder and rebuilding a life within the community. Recovery is facilitated or impeded through the dynamic interplay of many forces that are complex, synergistic and linked (Onken,



Dumont, Ridgway, Dornan & Ralph, 2002). This dynamic interaction among characteristics of the individual (such as personal attributes), characteristics of the environment (such as basic material resources), and the characteristics of the exchange (such as choice) can promote or hinder the process and outcome of recovery.

Recovery can be construed as a paradigm, an organizing construct that can guide the planning and implementation of services and supports for people with severe mental illness. A recovery oriented service and support system partners with the individual in identifying, building upon and expanding the capacities and competencies of the individual, his or her natural network and his or her community to achieve within that individual a sense of mastery over his or her psychiatric condition, a sense of constructive membership within that community, and ultimately, a sense of thriving. Such a conceptualization of recovery challenges providers, researchers and community leaders to rethink assumptions about the chronicity and pathology of psychiatric disorders and to develop strategies that change existing practices and beliefs at the personal, community and national level. Critical in this rethinking process is recognition of the role of self-determination and restructuring systems to support this approach to services.

### **Defining Self-Determination**

To say that behavior is self-determined, or determined by the self, is to say that behavior is experienced as autonomous. When we say self-determination, we essentially mean autonomy – self-governance. Self-Determination Theory (SDT) posits that *autonomy* is an essential ingredient of psychological health, growth, vitality, and

well-being (Deci & Ryan, 2000). More specifically, SDT equates autonomy with *volition*, or, the “desire to self-organize experience and behavior and to have activity be concordant with one’s integrated sense of self” (Deci & Ryan, 2000, p. 231). Autonomy is the co-occurrence of *integration* and *freedom*, and is a sense that one’s behaviors are intrinsically motivated and that one’s experiences and life outcomes are determined by the self (Deci & Ryan, 2000).

Intrinsically motivated activity represents the prototype of self-determined behavior, because it is engaged in spontaneously and naturally when people feel free to pursue their interests (Deci, 1975). Not only does intrinsic motivation increase one’s enjoyment of an activity, it also enhances performance, by encouraging creativity, cognitive flexibility, and conceptual learning (Deci & Ryan, 2000). Intrinsic motivation stems from an internal perceived locus of causality, that is, a sense that a behavior is autonomous, or, being caused by something internal to the self, rather than external.

Relatedness and competence serve to bolster autonomy and are also key components in self-determination (Deci & Ryan, 2000). Broadly speaking, SDT suggests that humans are “active, growth oriented organisms who are naturally inclined toward integration of their psychic elements into a unified sense of self and integration of themselves into larger social structures... [and that] it is part of the adaptive design of the human organism to engage interesting activities, to exercise capacities, to pursue connectedness in social groups, and to integrate intrapsychic and interpersonal experiences into a relative unity” (Deci & Ryan, 2000, p. 229).

## **Self-Determination and Recovery**

Self-determination is embedded as both a necessary process and outcome within the dynamic interaction of forces and factors that facilitate recovery. This actualization occurs within and builds upon the characteristics of the individual (such as gaining or regaining a sense of meaning and purpose), characteristics of the environment (such as supportive relationships), and characteristics of the exchange (such as independence). Self-determination does not occur in isolation. Efforts to develop, nurture or master self-determination will fall short without identifying and employing a threefold strategy that builds self-determination knowledge, skills and competencies in the individual, that facilitates self-determination enhancing environments and that promotes exchanges characterized by choice, interdependence and vital engagement. An emphasis that does not acknowledge and support such a threefold approach may hinder recovery by setting the person up for repeated failures in his or her self-determination attempts.

Despite the centrality of an ecological framework for understanding mental health recovery and the role of self-determination within recovery, there is a lack of attention to the environmental dimensions within this framework and their complex interrelationships and exchanges with the individual. The research and work of the *Mental Health Recovery: What Helps and What Hinders? A National Research Project for the Development of Recovery Facilitating System Performance Indicators*, is informative in addressing such shortcomings.

## **Recovery Helping and Hindering Service and Support Systems**

The What Helps and What Hinders Recovery Project originated as a collaboration by several participating states that had been independently exploring the idea of recovery-related systems performance measures. Mental health planners and administrators from these states formed a workgroup, to which they added consumers and researchers experienced and knowledgeable in the recovery field. The group recognized a need for additional knowledge about consumer/survivor perceptions of what helps and hinders recovery, beyond that available from the literature and the expertise available within the group. Accordingly they formed the five member research team (the majority of whom identified as consumers/survivors), who designed and launched the national project. The specific aims of the project are to: (a) increase knowledge about what facilitates or hinders recovery from psychiatric disabilities, (b) devise a core set of systems-level indicators that measure critical elements and processes of a recovery-facilitating environment, and (c) integrate items that assess recovery-orientation into national and state efforts for generating comparable data across state and local mental health systems and encourage the evolution of recovery-oriented systems. A group of federal, academic and private organizations<sup>1</sup> are

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<sup>1</sup> Center for Mental Health Services Survey and Analysis Branch, CO Mental Health Services, Columbia University Center for the Study of Social Work Practice, Human Services Research Institute, Mental Health Empowerment Project, MO Institute of Mental Health, Nathan Kline Institute Center for Study of Issues in Public Mental Health, National Assoc. of State Mental Health Program Directors National Technical Assistance Center & National Research Institute, NY State Office of Mental Health, OK Dept of Mental Health and Substance Abuse Services.

sponsoring the project and ten state mental health authorities<sup>2</sup> (SMHAs) are collaborating in carrying it out.

The work of the project is designed to evolve through three phases. Phase One used a modified grounded theory approach to capture the phenomenon of recovery and the ways in which the social environment, including the mental health system, impact upon the process.

Phase One has been completed, and much of this paper is centered in its results<sup>3</sup>, in particular, findings are highlighted in regards to formal service systems of care and treatment. Phase Two creates and refines prototype systems-level performance indicators, derived from the Phase One results, which will assess important elements and processes within mental health systems that facilitate or hold back recovery. In Phase Three, these recovery performance indicators will undergo large-scale pilot testing in participating states.

That recovery is a deeply personal journey was reflected in the richness, nuance and personal stories contained in the transcripts that resulted from the 10 structured focus groups with 115 consumers/survivors conducted during Phase One. Though the data reduction process meant loss of such uniquely personal detail, it did reveal the

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<sup>2</sup> AZ Dept of Health Services Div of Behavioral Health Services, CO Mental Health Services, NY State Office of Mental Health, OK Dept of Mental Health & Substance Abuse Services, RI Dept of Mental Health/Mental Retardation, SC Dept of Mental Health, TX Dept of Mental Health & Mental Retardation, University of HI-Manoa Adult Mental Health Div, UT Div of Mental Health, WA Dept of Social & Health Services Mental Health Div.

<sup>3</sup> *Phase One Research Report: A National Study of Consumer Perspectives on What Helps and Hinders Recovery*, has a full description of the research design, methodology, participants, findings and discussion and is available at <<http://www.nasmhpd.org/ntac/reports/index.html>> under the October 2002 listing. The reader is encouraged to review the full findings and discussion sections of Phase One Research Report.

many commonalities in people's recovery experiences and opinions. Recovery can be viewed by as process and a product of complex, linked and dynamic interaction among characteristics of the individual (the self/ holism, hope and a sense of meaning & purpose), characteristics of the environment (basic material resources, social relationships, meaningful activities, peer support, formal services, formal service staff), and the characteristics of the exchange (choice/ empowerment, independence/ interdependence).

### **Formal Service System Highlights**

Our findings support the notion that the formal service system, and the professionals and staff employed within it, constitute a key dimension that impacts upon recovery for many people with psychiatric disabilities. The research team clearly identified that progress toward recovery can be supported through the formal system. There was, however, within the data much more "hindering" content regarding formal systems than any other domain. It is critical to acknowledge that the formal system often hinders recovery, through bureaucratic program guidelines, limited access to services and supports, abusive practices, poor quality services, negative messages, lack of "best practice" program elements, and a too narrow focus on a bio-psychiatric orientation that can actually serve to discount the person's humanity and ignore other practical, psychological, social, and spiritual human needs.

Many of our findings lend further support to shortcomings already identified within the formal system of care. People have basic subsistence needs (such as a livable income, safe and decent housing, and transportation) that "the safety net" does not

meet. Social welfare and mental health programs are fragmented and difficult to access. People do not want to have to deteriorate in order to receive help, nor do they want to lose vital supports when they make progress toward recovery. Psychiatric services can be experienced as coercion and a means of social control, countering individual efforts of recovery. The experience of trauma and abuse was also notable across the focus groups – through the discussion of internalized stigma, the repeated traumatizations by the system, and the historical trauma of past abuse.

A staff-consumer relationship built on partnering and collaboration is viewed as the type of relationship that supports recovery. But the heavy emphasis on the power differential typical in the relationship between staff and consumers often inhibits recovery. The power differential is evident in, for example, the lack of meaningful consumer participation in treatment planning.

Our findings also showed that another critical dimension of recovery is consumer/ survivor self-help, consumer operated services, consumer/ survivor recovery role models, and consumer/ survivor movement involvement. The need for a large-scale expansion, funding, support and availability of peer services, such as peer support, education, outreach, role models, mentors and advocates was a common theme across all focus groups. Participants identified the need for alternative services and “experience experts/peer specialists” employed across all levels of mental health service provision. Limitations in funding, geographical availability, participation, and leadership development opportunities as well as a lack of transportation, and controlling and mistrustful professionals hinder such peer support efforts.

Our results also document the crucial role that choice plays in people's lives, a finding that has special implications for fostering self-determination in the formal service system. Participants are empowered when they make the choices regarding where they live, finances, employment, personal living/ daily routine, disclosure, who they associate with, self management and treatment. But too often quality of life choices seemed outside the realistic reach of many participants. Options are limited, lousy or nonexistent. Participants recounted service providers, professional and family members and communities that responded through the use of coercion, control, restricted access or involvement, discrimination and stigmatization.

Participants expressed independence, that is, not being subject to the control of others and not requiring or relying on others, as both a process and goal of recovery. Independence is achieved through making one's own choices and decisions, exercising self-determination, enjoying basic civil and human rights and freedom, and having a livable income, a car, affordable housing, etc. Some participants talked of the importance of both independence and interdependence, reaching beyond the goal of independence to that of embracing interdependence. Paternalistic responses, lack of respect, involuntary and long-term hospitalizations, stereotyping, labeling, discrimination, the risk of losing what benefits and supports one does have, all undermine both independence and interdependence.

### **Self-Determination within this Ecological Recovery Context**

As mentioned earlier, the premise of SDT is that individuals are inherently motivated to proactively extend and integrate their understanding of themselves, others,



and the world around them, and that this is necessary for optimal psychological functioning (Deci & Ryan, 2000; Ryan & Deci, 2000). SDT emphasizes the realization of one's true nature and that autonomy, competence, and relatedness are the three pillars of such self-actualization of one's potentials for psychological health and well-being (Ryan & Deci, 2001; Deci & Ryan, 2000). These are minimum requirements for psychological well-being as well as stipulations for social environments which foster thriving and enhance quality of life (Ryan & Deci, 2001).

For one to experience a behavior as self-determined, however, one must have a self-concept, or, a sense of self. For a certain behavior or outcome to be determined by the self, one must also have an understanding of the world around them, as well as one's relationship to the world. The concepts of self, world, and self-in-world, all bear significance on self-determination and are informed by the ecological context of recovery.

### **The Concept of Self within Formal Service Systems**

Park & Folkman (1997) suggest that self-concept is an abstract and relatively stable, but malleable, cognitive structure that is constructed through various meaning-making processes in response to the environment. Included in one's self-concept, or beliefs about the self, are enduring global beliefs about self-worth and perceived control, as well as the ways in which one constructs and perceives the self over time, or, one's identity.

Beliefs about self-worth involve feelings of loveworthiness, competence, morality, efficacy, and overall goodness, or self-esteem (Park & Folkman, 1997). Perceptions of

control involve one's beliefs about one's ability to control important outcomes and, more generally, one's life destiny (Park & Folkman, 1997). Beliefs about the world include how benevolent the world is and how trustworthy people are, and beliefs about the self in relation to the world are built upon the interaction of one's beliefs about the world and one's beliefs about the self. Park and Folkman also hold that global meaning also includes one's sense of purpose, or more specifically, beliefs that "organize, justify, and direct" one's striving (1997, p. 119). In the ultimate sense, these beliefs reflect one's goals, goal striving, and life purpose.

The process of recovery itself involves meaning-making, i.e., the development of hope, purpose, understanding and a positive sense of self, all through an active engagement with life (Onken, et al., 2002). For individuals recovering from mental illness, self-determination is reciprocally related to such meaning-making. Building self-confidence and self-esteem, often through incremental and successful attempts at engaging the world beyond self, fosters self-worth and growing sense of hope. Given hope, the recovering individual feels that he or she can have control over the destiny of his or her life. Such hope can be nurtured through a holistic view of the person as a human being and can foster the identification of a sense of purpose and active engagement with one's resulting goals, triggering self-agency. Self-agency engages and further develops self reliance, personal resourcefulness, self care, self advocacy and other competencies, all which hinge on self-determination. Exercising self-determination, which gives one a sense of control with regard to the meaning one

derives from experience, reflexively contributes to and generates this hope, purpose and self-agency.

But what in the current formal social service environment acknowledges the critical nature of, and fosters meaning-making processes? Dreams demeaned, pessimistic staff, services singularly focused on symptoms, emphasized chronicity and pathology, discounted spirituality, unwanted and long-term psychiatric hospitalization, stripped decision-making, and lack of education and information about one's condition, one's potential to recover and resources to make that possible, destroy hope, diminish purpose and act as roadblocks to recovery. Within such a system, self-determination efforts are undermined, devalued or resisted, all too often establishing a pattern of failure and resulting increased sense of helplessness and dependency. Potential meaning-making avenues in the community, such as work careers, civic involvement, the arts, parenting or religious organizations, provide their own set of challenges, chief among which is the risked rejection if one were to disclose psychiatric disability.

All these factors, experienced or perceived, have powerful negative effects on individuals' self-concept, esteem and sense of efficacy, triggering shame, fear, self-loathing, internalized stigma and further invalidation. Autonomy, an essential ingredient of psychological well-being, is achieved through self-governance. Self-determination, the means to this end, cannot occur without a concept of self. It is ironic that just as we are making strides in cognitive behavior therapy, cognitive rehabilitation, integrated psychological therapy and other interventions to develop problem-solving, social and behavioral competencies that strengthen one's sense of self, increasingly restricted

public services and diminishing health care coverage prevent their access or worthwhile use.

### **The Social Dimension of Self-Determination within Formal Service Systems**

Recovery also involves the social/emotional support dimension of secure relatedness - a core of active, interdependent social relationships - being connected through families, friends, peers, neighbors and colleagues in mutually supportive and beneficial ways. Believing that recovery is possible and having this belief supported by others (friends, family, peers and staff) helps fuel intrinsic motivation. Social and personal isolation, however, emotional withdrawal, controlling relationships, poor social skills, immigrant status, disabling health and mental health conditions, past trauma, and social stigma impede this social dimension, undermining the sense of relatedness and reinforcing the lack of security or stability in such connections.

No where was this more evident than in consumer-staff relations. People do not want to interact with neutral detached helpers, nor do they want to meet a new professional or paraprofessional each time they seek help. One cannot establish a secure relatedness with staff who are disrespectful –condescending, not listening, infantilizing, having low expectations, being culturally insensitive, uncaring, untrustworthy, and devaluing. These attitudes hinder people’s sense of self, and undermine motivation, self-determination and recovery.

True partnership, having the sense that you are viewed and respected as an equal, and that the other person will be there through thick and thin, conveys secure relatedness and fosters intrinsic motivation. Having opportunities for choice and

negotiation in selecting a doctor, therapist or case manager, having complete and accurate information on all possible interventions and supports, real collaboration development of individual treatment plans, foster recovery. The focus of the helping relationship shifts to the actualization of the individual through self-determination and choice.

Another critical social dimension of recovery and that of secured relatedness, is consumer-to-consumer connection. Such connections provide social support, opportunities to help one self through helping others, experiential knowledge (including sharing alternative world views and ideologies), role models, and sense of normalcy and understanding. It is one venue that can counteract the internalized life scripts regarding chronicity, pathology and helplessness, replacing these with an emphasis on self-responsibility and self-management. When individuals feel responsible for their behavior, positive feedback increases intrinsic motivation and negative feedback decreases it, as long as this information does not diminish one's sense of autonomy (Deci & Ryan, 2000). The tacit knowledge base (i.e., those things that one knows through having lived the experience), however, that constitutes consumer-to-consumer connection is not fully valued or accepted in professional circles, nor funded.

### **The Instrumental Dimension of Self-Determination within Formal Service Systems**

Recovery also involves several core instrumental (i.e., concrete) support dimensions. But the conditions placed on receiving instrumental support can undermine self-determination and thus sabotage recovery. Intrinsic motivation, critical to experiencing behaviors as determined by the self, can be undermined by external

rewards (Deci 1971; 1972), threats (Deci & Cascio, 1972), surveillance (Lepper & Greene, 1975), evaluation (Harackiewicz, Manderlink, & Sansone, 1984), and deadlines (Amabile, DeJong, & Lepper, 1976). All have the propensity to shift one's locus of causality from internal to external, making one feel less like the origin of one's behavior, and so, less autonomous, and less responsible for it, ultimately, diminishing intrinsic motivation. External motivators like threats and deadlines undermine one's sense that an activity is self-initiated, and hence, decrease the amount of autonomy experienced during that activity, leaving one's need for autonomy unfulfilled.

Poverty; unsafe, substandard and segregated housing and neighborhoods; inadequate or no medical and other benefits; all undermine recovery. What assistance is available – SSI, SSDI, Section 8 housing, Medicaid – neither fully alleviates these conditions and too often are experienced as demeaning within their own right. People are belittled for what assistance they do get, questioned, monitored and threatened as to their need or qualification for such. The formal social service system is experienced as a gatekeeper, intent on shaping and controlling the lives of those who receive benefits. Widespread fears of the risk of losing assistance forces people to amplify, intentionally or through self-fulfilling prophecy, what is wrong with them, their dependency, vandalizing their intrinsic motivation and sense of self-governance.

Employment offers a way out of this dependency, but unemployment is the norm regarding psychiatric disability, regardless of how strong the desire and how persistent the effort is to get work. People are confronted with a very limited range of jobs, or find themselves underemployed, in stagnant jobs. Even when one is successfully

employed, fear persists concerning how employers and co-workers will react if they find about one's mental illness. Advanced education and training is seen as a way of improving one's employment chances, but people lack access to such opportunities. Unemployment, underemployment, exploitation (in the form of volunteer labor), disincentives (loss or threat of loss of benefits), prejudice and discrimination - the loss of meaningful work or student roles - can be accompanied by the loss of core identity component, that of a sense of productivity and purpose.

The formal service system, and the professionals and staff employed within it, constitute another instrumental support dimension. While there is much discussion of moving towards a recovery orientation and many notable efforts being implemented, psychiatric services and staff are far more often experienced as a means of social control, countering individual efforts at reestablishing and maintaining an internal locus of causality and intrinsic motivation, ultimately diminishing autonomy and recovery. Such systems are characterized by controlling professionals and staff and power inequities. At the core of such hindering forces is the operationalization of societal response to mental illness, that of shame and hopelessness and the need to assert social control over the unknown and uncomfortable.

The illness and crisis orientation of the formal system overly medicalizes and pathologizes people's life experiences. In medical model systems every experience, need and concern comes to be viewed as a symptom of a mental illness and in need of control - at the expense of seeing consumers as whole unique individuals. When the system is crisis-oriented, the person's condition has to deteriorate and reach the level of

crisis or emergency before they can receive help. Services emphasize crisis stabilization, medication and medication management, but this alone is too limited a strategy to assist people in achieving recovery.

This orientation is too often infantilizing and dependency-engendering, the antithesis of self-determination and autonomy. The attitudes, culture, policies and traditions of such systems operate from the perspective that the client is inferior to staff. The formal system does not support the development of self-responsibility; the system decides for you what you want or need based on what it is prepared to provide. There is a lack of access to services that are based on self-defined need. Often inadequate information on the help, resources and treatment options is provided. People lack illness education/ patient education, including information on diagnosis, practical education on self-care and how to improve. Families lack needed education and support. The broader community lacks awareness and information about psychiatric disorder and recovery. The lack of education, choice, selection, needed range of program/ treatment options, and continuity of care and of caregiver undermines secure relatedness and decision making competencies needed for self-determination.

Many systems still rely on coercion and force, such as coerced consent forms, court mandated services, forced medication, mandated connections, and being forced to accept treatment in order to receive other assistance. Staff often relate to consumers paternalistically, controlling by pressure, threats and force. Forced treatment, threats and other forms of coercion serve as external motivators that hinder an internal locus of causality and undermine intrinsic motivation and the ability to relate as a responsible



person. Coercive systems limit and remove choices, and can use treatment, services, and medication as means of social control. Acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from *undue external influence or interference* actualizes self-determination, and is not possible in coercive service systems (Sands & Wehmeyer, 1996).

The formal service system and many of its personnel also largely overlook how responding to and coping with trauma is a central experience of psychiatric disorder and thus fails to incorporate trauma knowledge in existing explanations of, and responses to, mental illness. A trauma sensitive and healing culture is one of belonging, safety, openness, participation, citizenship and empowerment – an environment that fosters thriving and enhances quality of life, actualizing self-determination and autonomy (Bloom, 1997). Pivotal in creating such an environment is the support of peer services and peer specialists, both independent of and integrated into existing service delivery systems.

### **Concept of Self-in-World: A Vision for Self-Determination in Formal Service Systems**

The concept of self-in-world (i.e., the nature of the exchange relationship between self and the world), bears particular significance on self-determination. Three types of exchanges, choice making, interdependence and vital engagement, are of critical importance.

#### **1. Choice**

An exchange characterized by having choices among meaningful options, having competencies in making choices, and having the ultimate decision making power

regarding the choices, not only fosters self-governance and self-responsibility, but becomes a exchange in which people flourish. Intrinsic motivation and autonomy are enhanced by providing choice (Zuckerman, Porac, Lathin, Smith, & Deci, 1978) and acknowledging a person's inner experience (Koestner, Ryan, Bernieri, & Holt, 1984). Access to relevant, accurate information becomes critical, as people want to understand what they are experiencing, they want to be educated and actively participate in making important choices.

Exercising meaningful choices free from *undue external influence or interference*, which inherently incorporates the principles of self-determination, must be recognized as the recovery method for engaging people and making services meaningful to them as individuals. People want the freedom of whether, and how, to participate in programs, medications, and services. But choices must not be limited to the realm of treatment. They include where one wants to live/housing, finances, employment, personal living/daily routine, disclosure of disability, choosing how one sees one's self, one's disorder, one's situation, quality of life, who one wants to associate with and self management. To have choice, options are necessary and must include alternative paths that are accepted as legitimate choices, or at least not blocked.

Choice is something that involves a learning curve. People need opportunities for choice-making and to build choice making competencies. Psychiatric services, however, often are experienced as a stripping away of choices, personal control, and decision-making. Dependency is created, self-doubt is fostered, choice-making competencies are lost. Thus a relearning process may need to activated, starting small

and progressing to more challenging or complex choices as one regains confidence and experiences success. It helps to have support. People may need assistance in recognizing that they do have choices and are capable of making choices. Time and patience must be respected as a person develops choice-making skills. People benefit from knowing about what choices are available and when their choices are being limited.

With the exercise of choice comes the importance of taking responsibility for choices. This includes the right to take risks, make a mistake, and to fail. Thus, taking responsibility for making choices needs to coincide with opportunity to make choices. Choice-making competencies, and thus self-determination competencies, can develop through constructive processing of, and learning from one's mistakes and failures.

At the same time that people want the freedom to choose "to be who I am" they also express the opinion that they would like to share, collaborate and partner with others in their recovery process. They want ultimate control of their own lives, but recognize a role for others who are willing to share in the decision-making, provide feedback but not take over or take control away from them. Falck (1988) suggests that self-determination can only be achieved within such a social context, using the term social self-determination to recognize that people and their actions are inextricably interlinked. Schwartz (2000) offers up the observation that "[i]t is self-determination within significant constraints – within rules of some sort – that leads to well-being, to optimal functioning" (p. 81). In a follow-up article, Schwartz clarified that rather than thinking of it as rules, to think of it as guidelines flowing out of "a substantive vision of a

good (healthy, productive, socially responsive and responsible) human life” (2001, p. 81).

## **2. Interdependence**

Clearly, people need people, and self-determination totally unconstrained can push people to an autonomy that can be disconnecting. Covey (1989), introduces a maturity continuum, and suggests that dependence is the paradigm of you; independence is the paradigm of I; and interdependence is the paradigm of we. Interdependence is a term that implies an interconnection, or an interrelationship between two entities. Martin Luther King, Jr., summarized this when he stated:

"In a new sense all life is interrelated. All persons are caught in an unescapable network of mutuality, tied to a single garment of destiny. Whatever affects one directly affects all indirectly. I can never be what I ought to be, and you can never be what you ought to be until I am what I ought to be. This is inter-related to the structure of reality." (Carson & Shepard, 2001)

Interdependence is about relationships that lead to a mutual acceptance and respect. Although it recognizes that all people have differences, as an organizational paradigm for guiding self-determination, it promotes an acceptance and empowerment for all. It suggests a fabric effect, where diverse people come together in a synergistic way to create an upward effect for all. The interdependent paradigm defines the problem not from what is wrong with the person, but from the context of limited supports to allow the person the opportunity to participate and advance (Condeluci, 1991). That is, rather than look at deficits or limitations that people have, it repositions the problem

to be deficit in service system and/or cultural-social structure by not having appropriate supports for full participation for all. It suggests a narrowness of supports, rather than an incapability of certain people to participate.

This fundamental shift in problem perception is critical to a comprehension of interdependence. For example, is the problem of unemployment because people have psychiatric disabilities, or because we don't have adequate job supports? People must have the right and privilege to determine their own situation; they are capable of recognizing their own reality. This shift also challenges the cycle of dependency and devaluation that people with psychiatric disabilities experience in their self-in-world exchanges. People desire a partnership relationship with professionals, where one is listened to, believed, asked for their opinion, and treated equally. But many people express hesitation to share with professionals the realities within their own situation, that they will be misunderstood, perceived as complaining or noncompliant or that what they share will be used against them as further evidence of their illness and pathology.

Essential within an interdependence paradigm is empowerment. The process of recovery itself also involves empowerment, i.e., an awareness of the circumstances of one's illness, the desire and will to alter these circumstances, and a feeling that one has the power to effectively recover, due in part to the strength of internal and external resources (Onken, et al., 2002). For individuals recovering from mental illness, self-determination is reciprocally related to empowerment. The empowerment process may serve to cultivate both self-determination and meaning. Through knowledge, awareness, and insight, empowerment puts recovery into the hands of recovering

individuals and groups, allowing them to determine the pathway to mental health for themselves. Empowerment also motivates the recovery process by inspiring hope, and infusing the lives with meaning and purpose, necessary for the strengthening of concept of self, self-direction and self-determination.

Condeluci (1991) articulates core elements of the interdependent paradigm that are designed to promote and empower the distantiated person to take more charge of his/her life. One core element is that the people must have the right and privilege to determine their own situation. They are quite capable of recognizing their own reality. Those around the person who has been devalued must appreciate, acknowledge and accept the individual's definition of the situation. Accepting the person's definition is an important element of empowerment (Gutiérrez, 1990). For people to tap this power inside, they must have an opportunity to explore the dimensions of their self-esteem and self-direction. The California Task Force to Promote Self-Esteem and Personal and Social Responsibility (1990) suggest the following themes are vital to self-esteem and self-direction: appreciating one's worth and importance, appreciating the worth and importance of others, affirming accountability for one's self, and affirming one's responsibility toward others. Might not these serve as starting points for the significant guidelines that Schwartz suggests are needed for self-determination that leads to well-being, to optimal functioning?

Another key element of interdependence is found in relationships. Within the interdependent paradigm, it is essential that people have adequate opportunities to establish a wide range of relationships. To this extent, experiences that will promote

non-threatening exposure and relationship building to others outside the formal system are critical. People with psychiatric disabilities, however, often describe inadequate network of friends, family, peers, other sources of social contact and mutual aid, as a cause of isolation that hinders recovery. Individual emotional withdrawal further reinforces the absence of a social network. A lack of practical information and education on mental illness and wellness for families and friends is widespread, and the resulting lack of understanding compounds distrust and inhibits both individual efforts at establishing secured relatedness to one another and the capacity of potential support. A lack of opportunity and locations for learning and practicing social skills contribute to isolation, both within the general community and from consumer/survivor peers. As a result, the most important (and controlling) relationships in the lives of people with psychiatric disabilities often become the experts and paid staff that surround them.

Since the interdependent paradigm accepts people as they are, another core element is to acknowledge and develop supports. We all need and use everyday supports to make our lives more enriched. The same spirit should surround the way we relate to people with psychiatric disabilities. In other words, we need to allow for the unique manifestations brought on by a person's or group's "difference," and to get people the supports that will help them address the presenting problem and get on with enjoying life. *Achieving independence moves from being measured by the quantity of tasks one can perform by him or herself, to that of the quality of life one can have with supports* (Zolla 1986). But people with psychiatric disabilities feel they are viewed as source of billing or as a commodity that generates revenues, rather than as unique

individuals with unique needs and personal freedoms. Formal services have an inflexibility, or rigidity, that doesn't match well with changing or dynamic individualized needs. People are fitted into services and programs rather than services and supports being tailored to people. When resources are tied to levels of care or functioning, program guidelines or the funding of certain programs, services that facilitate self-responsibility and recovery can be denied.

Another core element of interdependence is recognizing that broader, more sweeping actions must be promoted. Opportunity is a critical goal for interdependence. People need to have chances before they grow. In many regards the barrier to opportunities for people with psychiatric disabilities is found in cultural and societal injustice. To this extent, then, interdependence must also look toward our macro-system for change. These are actions that challenge the status quo and attempt to reframe the systems and structures of society that keep people harnessed and separate. Interdependence demands that whenever “new” is achieved, it must remain in the spirit and integrity of consumer control and dignity.

A focus on capacities is the remaining core element of the interdependence paradigm and is embedded also within the empowerment process. It is not akin, however, to a strength/needs approach. The concept of capacities is different from that of strength. Usually strength refers to the things that the person can do that are defined by others as important. Capacities not only encompass strengths but much more. Capacities can be interests, preferences, attributes, or gifts that may or may not have



anything to do with activities, skills or other aspects that are considered important. This focus on capacities has the potential to tap into vital engagement.

### **3. *Vital Engagement***

Opportunities for meaningful activities and engagement in life constitute the final dimension of self-in-world exchange that constitutes a vision for self-determination in the mental health system. According to Nakamura and Csikszentmihalyi (2003), vital engagement is at once both a developmental outcome and process; it is an “optimal developmental outcome” (p. 83), which is characterized by participation in an enduring relationship with the world that is inherently enjoyable as well as meaningful. “In vital engagement, the relationship to the world is characterized by completeness of involvement or participation and marked by intensity” (Nakamura & Csikszentmihalyi, 2003, p. 86). It is a relationship to the world that is characterized both by flow, or enjoyed absorption, and by meaning, or subjective significance. In such relationships, one becomes so engaged and engrossed with some activity providing experiential rewards in the here and now because of its recognized worth that there is no felt distinction between self and activity.

Nakamura & Csikszentmihalyi suggest that in vital engagement, the object of the self’s directed attention can be anything, from a cultural domain like poetry or a person, group, institution, political cause, job, or something else, but it is characteristically experienced as significant and worthy of attention. This attention is experienced as intrinsically motivated, that is, willingly invested rather than coerced. The object is

significant and worthy of attention specifically because valued aspects of the self are absorbed or invested in the relationship as well as realized and expressed through it.

The experience of intense enjoyment in a particular activity to the extent that sense of time passing is lost is known as flow. Flow can be experienced any activity, so long as a person feels that they can optimally utilize their skills and develop new ones from the challenges inherent in it. Flow can be experience in work, love, play, or duty. Because the dynamics of flow align optimal subjective experience with the stretching of capacities, to find flow in what one is doing is to *grow* (Nakamura & Csikszentmihalyi, 2003). This growth may spur the development of entirely new relationships and long-term goals, as people are motivated to reproduce their positive subjective experiences. In this way, an individual's set of enjoyed pursuits expands over time to the extent that one finds oneself exposed to new activities. Exposure to new activities might be the result of chance encounters, or their introduction by other people, communities, or institutions (Nakamura & Csikszentmihalyi, 2003).

The felt significance of an enjoyed relationship develops initially through one's attraction to the object. In this regard, rather than being born into meaning, or being forced to make sense of negative experiences, a person can derive a sense of global meaning as it emerges from their positive experiences and vital engagement with the object. This sense of meaning and significance deepens over time, as one continues to engage with the object and is perpetuated in part through one's membership in a community of practice and interactions with other members of the community (Nakamura & Csikszentmihalyi, 2003). In this regard, mentors, peers, and students

may all serve to invigorate one's relationship with enjoyable objects or activities. Such interactions with members of the extended community not only enrich and invigorate vital engagement, but promote its evolution over time (Nakamura & Csikszentmihalyi, 2003).

The importance of vital engagement and its relationship to meaning making, growth and competency building, and thus the facilitation of self-determination is not recognized or promulgated in formal service systems. Access to, and choice among, meaningful activities, in particular work opportunities and career development, is fundamental to recovery. Meaningful, flexible employment is described by many as the best therapy there is. Other avenues of meaningful activity include engaging in knowledge development and educational opportunities – the intrinsic value in learning, volunteer work and artistic expression. But rather than experiencing encouragement and support for such efforts, people with psychiatric disabilities often describe their experiences as consisting of long bouts of overmedication (zombie like states of standing around, smoking cigarettes and drooling on their feet), forced engagement in meaningless day treatment tasks, and underemployment in dead end jobs.

People with psychiatric disabilities also describe engagement in advocacy as a means to gaining voice, of moving towards self-determination and recovery. Personal or self-advocacy is integral to self-determination; group or systemic advocacy activities can trigger referent power opportunities. Often advocacy involvement starts by connecting with peers (attending meetings and sharing experiences) and then seeing others undertake advocacy. Being a part of situations in which others engage in

advocacy can trigger one's own sense of power. Sharing what it is like to experience ignorance, injustice, stigma and inequalities, and validating that these are common occurrences, helps provide people with a sense of being members of the extended community (Nakamura & Csikszentmihalyi's assertion) and the strength to speak up. Channeling anger concerning injustice give people the energy to seek change, both personal and political. Advocacy involvement can provide purpose and vital engagement when other opportunities, such as employment, are taken away or restricted and/or employment is too difficult to sustain due to the disorder itself, or when a person feels dependent and possibly trapped on government benefits. Advocacy, civic and artistic involvement opportunities also extend beyond the mental health system, but supports to engage in such are rare or nonexistent.

### **Conclusion**

We can more fully actualize the ecological context of recovery for people with psychiatric disabilities when we foster self-determination. A recovery-enhancing system is person-oriented, and respects people's lived experience and expertise. Optimal mental health is achieved when one's experience is that of being self-determined. Self-determination is encouraged when basic needs for autonomy, competence, and relatedness are met. Such a recovery-focused and autonomy enhancing environment promotes choice-making and self-responsibility. It addresses people's needs holistically and contends with more than their symptoms. Such an environment meets basic needs and addresses problems in living. It empowers people to move toward self-management of their condition. The orientation is one of interdependence and hope

with an emphasis on acceptance, positive mental health and wellness. It fosters creative supports and assists people to connect, including mutual self-help. It focuses on positive functioning in a variety of roles, vital engagement in meaningful activities, and building or rebuilding positive relationships. These core elements can serve as the foundation of a system of care that promotes self-determination and recovery for individuals with psychiatric disabilities.

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# The Promise of Self-Determination for Persons with Psychiatric Disabilities

*By Thomas Nerney, Director, Center for Self-Determination*

## Introduction

Individuals with psychiatric disabilities represent the largest category of persons with disabilities in the United States. No other category of disability is treated so disparately and remains so inadequately funded that it can truly be said that no coherent national finance policy exists for this population. In the last decade public policy for individuals with physical and cognitive or intellectual disabilities has gradually been coalescing around several important themes. These themes all lead toward greater recognition of community participation, income production or work, control over resources and leading meaningful lives that resemble in all-important respects the aspirations and ambitions that all Americans have for themselves. This is not to say that these goals have been realized or that the impetus to achieve them does not vary from state to state.

In order to expand on the work of those with psychiatric disabilities, allied clinicians and committed family and friends, this paper attempts to organize an agenda around the implications of self-determination for those with psychiatric disabilities that:

- Suggests important parallels with the self-determination movement among those with intellectual and cognitive disabilities
- Recognizes that funding streams and public dollar investments differ considerably among various disability populations



- Analyzes these difficulties and more in one state (Michigan) that has developed positive public policy with an invitation to embrace self-determination toward those with significant psychiatric disabilities
- Recommends a formal expansion of quality assurance in mental health to encompass not just treatment and recovery issues but issues of living and working in community
- Recommends several courses of action with regard to both public policy and financing in order to meet the promise of self-determination for individuals with psychiatric disabilities. *These concrete recommendations are meant to build on the general ideas explored and advanced in the President's New Freedom Commission Report.*

This paper then is an exploration of the meaning of self-determination as it moves across all disabilities with an emphasis on the importance of including those with psychiatric disabilities in the growing movement to literally restore citizenship to individuals with these disabilities.

### The History and Meaning of Self-Determination

#### **The Promise of Self-Determination**

The promise of self-determination from its inception was rooted in increased quality, increased power for individuals with disabilities, increased status within the community for these same individuals and, at the policy and organizational level, a fairer, more equitable distribution of public funds. It was just over a decade ago that the first demonstration on self-determination in New Hampshire began with a grant from the Robert Wood Johnson Foundation. The two populations included in this initial pilot were individuals with developmental disabilities and individuals with acquired brain injury.

The original monograph outlining the general goals of this fundamental shift were spelled out in *An Affirmation of Community* (Nerney, T. and Crowley, R., 1994) This monograph outlined the “harm” that resulted from typical human services for these populations. Self-determination was not some form of rugged individualism but rather recognition of our inter-connectedness and shared vulnerability. This included loneliness, isolation and increased expenditures of public dollars with no concurrent set of positive outcomes.

This fundamental shift in power was predicated on the human service system adopting structural changes that would facilitate and hasten the shift in power necessary for self-determination to become a reality for tens of thousands of individuals presently served and for those tens of thousands currently awaiting public dollars for support. At its heart, self-determination was committed to fiscal conservatism. Better put, the self-determination movement was committed to obtaining better value for the dollars currently expended. Self-Determination then, under this rubric, became organized around a set of principles rather than a set of human service interventions or environments. These principles were not human service categories and tried to capture both the political significance of this change and the implications for individuals at a very personal level. *Beyond Managed Care* (Nerney & Shumway, 1996) outlined these:

**Freedom**, the opportunity to choose where and with whom one lived as well as how one organized all important aspects of one’s life with freely chosen assistance as needed; **Authority**, the ability to control some targeted amount of public dollars; **Support**, the ability to organize that support in ways that were unique to the individual; **Responsibility**, the obligation to use public dollars wisely and to contribute to one’s community. In 2000 at the request of the national self advocacy movement The Center for Self-Determination added **Confirmation**, the recognition that individuals with disabilities themselves must be a major part of the redesign of the human service system.

## **Increased Quality**

Increased quality as a cornerstone of self-determination emerged from the recognition that quality was importantly related to two dimensions that were inherently lacking in the lives of so many individuals: deep, personal relationships and elementary freedom. It was apparent in the early 1990s that individuals served by the human service system lacked the ordinary freedoms that all Americans take for granted. These included the right to establish where and with whom one lived as well as more mundane freedoms associated with what to eat, what time to go to bed and other decisions that go to personal habits all other individuals in this society take for granted. This included the realization that highly personal goals were so often subjugated to an annual plan that substituted human service and behavioral goals for the very real aspirations of individuals with disabilities.

Equally as important was the perceived lack of personal relationships grounded in friendship, romance and family. The vast majority of those served twenty-four hours each day, seven days a week, lived without both close relationships and elementary freedoms. There was no expectation that the human service system would listen to their dreams or aspirations nor encourage high expectations. What passed for quality was little more than liability assurance for health and safety. The stunning insight of the early days in forging the self-determination movement was the realization that even health and safety could be easily compromised without close personal, committed relationships. And so it became imperative to fashion a new approach to quality that relied on the perspectives of individuals with disabilities and close family and committed friends to determine what constituted quality. This notion of quality became deeply rooted then in the very foundation and promise of self-determination.

## **Increased Power and Authority**

There was no easy way to say it. This new notion of what constituted quality demanded that control of the resources move from those who presently

controlled the human service system directly to individuals with disabilities and their allies. Every attempt at fashioning quality without moving power over resources and decision-making resulted in a continuation of some form of paternalism and resulted very often in compromises that adversely affected the quality sought. This necessitated the creation of highly personal and individual budgets that melded person centered planning with person centered budgeting. One of the hallmarks of a person-centered budget became flexibility. Flexibility in where and with whom one could purchase supports and flexibility in changing and prioritizing line items as a person's experience changed and priorities were reset. The simple and straightforward "tools" of self-determination were spelled out in *Communicating Self-Determination: The Tools of Self-Determination* (Nerney, 1999) These three tools were individual budgets, independent support coordination and fiscal intermediaries. All were necessary in order to deal with the inherent conflicts of interest in the present human service system. The Federal Medicaid Agency, CMS, has virtually adopted these tools as requirements for states submitting Waiver applications under the Medicaid program for self-determination.

### **Increased Status within our Communities**

Central to this new notion of quality was the issue of status or recognition of the individual with a disability as a responsible, contributing member of society. Interview after interview with persons with disabilities revealed a deep desire to work, produce income and contribute or "give back" to the community where the person lived, as well as enter into meaningful relationships. Self-Determination as a movement then began to address the status of persons with disabilities and recognize the implications of enforced poverty and lack of meaningful work for the vast majority of those served by the present system.

The first step in this evaluation of the current status of individuals served by the human service system was the understanding that most of these same individuals did not even engage in culturally appropriate activities during the day

and frequently lived in environments that were perceived as human service environments rather than community environments. The lack of real income as a contributor to personal isolation and lack of reciprocal-based relationships was the next step in understanding just how important this lack of status was for so many people. As a result a new sense of economic justice began to pervade the self-determination movement. Small demonstrations quickly revealed that lack of income was almost solely a residual by-product of the organization of human services not a result of the significance of a person's disability. One of the new, clearly articulated goals then became "the production of private income for everyone". For those without the physical skills or interest in typical jobs, the development of microenterprises became an alternative that greatly enhanced both the community integration of these individuals and made possible the kinds of purchases that went to the heart of reciprocal relationships and true community memberships. This new but important dimension of self-determination was spelled out in a University of New Hampshire monograph, *The Importance of Income*, in an essay entitled *The Poverty of Human Services* (Nerney, 1998)

### **Policy and Organizational Change**

The promise of self-determination then began to rest on the creation of new policy and the institution of structural change. Policy itself may not be determined without those most affected assuming an integral role in policy development. This meant that the self advocacy/consumer movement had to become a priority everywhere and that systems had to commit to support all the dimensions of self advocacy including its political dimension. Support for an enhanced role for families and community members also became imperative.

The structural changes necessary to accomplish this were becoming more and more apparent. The "Tools" were gradually seen as absolutely essential because it became more and more apparent that human service systems were not only incredibly complex but were rife with conflict of interest over both money and power or status. Individuals with disabilities, families and allies had to have

uncompromised or “conflict of interest free” assistance in order to navigate the complexities of the funding authorities, the personal planning and budgeting necessary to craft a meaningful life-plan and the authority to adequately represent the person with a disability. This new function was referred to as independent support coordination and/or independent brokering.

Two other structural changes mentioned above needed to be put in place as well: fiscal intermediary organizations that would protect the integrity of individual budgets and individual budgets that were highly personal and unique. There turned out to be many ways to develop fiscal intermediaries from simple bill paying companies to organizations that would assist in compliance with federal and state regulations regarding tax and labor issues as well as key employment issues. The creation of highly personal and unique individual budgets became central to the implementation of self-determination. They also became the most problematic precisely because individual budgets under self-determination raised all of the conflicts of interest in the present system and represented a stark departure from typical human service contracts. This issue went right to the heart of equity in the allocation of long term care dollars as well.

The present system did not understand well the inherent conflicts of interest in the present case management systems that relied so heavily on paper compliance, huge caseloads and untrained individuals in the elements of self-determination. Even those systems where case management was separate and independent of service provision there was neither the time nor often the inclination to reform the system to make it more responsive. While purists will claim there is only one way to provide this function, in fact, experience has shown that there may be several ways.

The organizational changes that must be in place then include conflict of interest-free support coordination with adequate authority to represent each person with a disability; the removal of the sums allocated to an individual from existing or

future provider contracts and deposited exclusively for each person within a fiscal intermediary organization; and, the creation and support of a highly unique individual budget with maximum flexibility. This later structural change must include the ability to purchase directly from community organizations and individual members of the community as well as from existing provider agencies that enter into contracts with individuals for discrete supports of various kinds. It is entirely possible that the psychiatric disability community will create new forms of these structural changes. For example, in some parts of the country individuals with disabilities can hire virtually anyone they choose to provide independent brokering. This function does not have to be a traditional professional service.

This particular strain of self-determination that we began just over a decade ago has deliberately eschewed psychosocial and pedagogical views of self-determination. There are those who focus on “teaching” self-determination skills (Wehmeyer, 1996) and, while this may be appropriate during school, it contains a very dangerous element. If self-determination ever loses its focus on basic human and civil rights then the hazard will be that professionals will once again determine when individuals with cognitive, physical, intellectual or psychiatric disabilities are “ready” to exercise those freedoms guaranteed by the Constitution and The Bill of Rights.

The actual implementation of real self-determination has been often difficult, fraught with compromises and resisted by many stakeholders. It is important for those with psychiatric disabilities and their allies to understand this history, understand as well the additional barriers they face in an inadequately funded system, in order to create an agenda for change that will make self-determination a real possibility.

## Michigan

Michigan Department of Mental Health

July 18, 2003

Persons who rely on the public mental health system for necessary supports and services must have access to meaningful options from which to make choices, and be supported to control the course of their lives. Arrangements that support self-determination must be sponsored by the public mental health system, assuring methods for the person to exert control over how, by whom, and to what ends they are served and supported.

This new 13 page policy directive from the Michigan Department of Mental Health spells out the obligations and the responsibilities of both the Michigan Community Mental Health Boards and the consumers of typical mental health services. Michigan then becomes the first state in the United States to formally offer self-determination to those in the mental health system as well as those with developmental disabilities served by these same mental health authorities.

Michigan in many ways is representative of the difficulties that states encounter when they embrace self-determination. While self-determination has been voluntary up until July of 2003, several mental health authorities made major commitments to implement it for individuals with developmental disabilities. Many ignored it and some took small steps to both learn and to experiment with very small numbers. The fundamental shift in both structure and values indeed proved difficult on a statewide basis. But the difficulties encountered with individuals with developmental disabilities are more manageable than what mental health authorities will encounter for those with psychiatric disabilities.

The actual deployment of resources and the amounts of dollars available for those with psychiatric disabilities differ substantially from those with developmental disabilities. With an average long term care Medicaid expenditure



of about \$55,000 Michigan is above the norm on spending for those with developmental disabilities. Coupled with a managed care waiver that mandates that everyone be served, Michigan is better positioned to reallocate resources for those with developmental disabilities in ways that comply closely with the utilization of fiscal intermediaries, independent support coordination and individual budgets. One of the reasons is that so much of the spending for this population is invested in personnel who provide direct supports of one kind or another. The same cannot be said of those with psychiatric disabilities.

In too many instances resources in this system are targeted to clinical professionals and ignore basic housing needs. When dollars are spent on some aspects of self-direction such as peer clubs the dollars are pooled. Sorting out the public dollars deeply embedded in the current system will be complex.

The dollars for those with psychiatric disabilities tend to get invested into clinical services. The dollars for those with developmental disabilities were invested more heavily in group home and other community settings. In Michigan today three quarters of all those served by the public mental health authority are persons with psychiatric disabilities. However, only about 45% of the Medicaid resources are directed at their support resulting in an average per capita expenditure of about \$6,000. (Estimates vary)

As Michigan attempts to valiantly implement self-determination, people with psychiatric disabilities still fall through the cracks, experience homelessness in great numbers and live in abject poverty in greater numbers than any other population. In fact, in July of 2003 the Governor of Michigan declared that there was a crisis in mental health and vowed to correct it. (Detroit News, 2003)

The sheer numbers of individuals who need support, state budget considerations, low per capita investments and large bureaucracies all contribute to the difficulty of implementing self-determination in a state with a reputation for

at least acknowledging the need to address the problems and having the courage to begin. The same cannot be said for some other states.

## **Quality and Self-Determination**

In the field of developmental disabilities issues of quality have been paramount for some time. Very gradually quality assurance has moved from simply ascertaining the person's health status to asking the person with a disability about various levels of satisfaction and more recently what choices the person is able to make over important program and living and working arrangements. The goals and the implications of self-determination are now beginning to take us much further as we look more closely at the best that contemporary quality assurance systems promote. At the Center for Self-Determination we have become convinced that we must take this notion of quality to another level and move from simple satisfaction with services and supports to control of those supports and a new view of quality.

This means that for self-determination the essential standard for quality will no longer be based on satisfaction with supports and services. Rather, we believe that quality assurance needs to become normed on universal human aspirations. The implications are enormous. Instead of asking the person with a disability if they are "satisfied" or even had some choice about where they live and with whom they live, or "satisfied" with mental health services provided, we recommend that the person be asked if they were able to choose typical housing arrangements, live with another person only by mutual consent, and have authority over who comes in the front door. The same goes for what individuals do during the day. Instead of asking if they are satisfied with a day or vocational program, the new questions turn on the amount of money earned each week, the number of hours worked and the amount of disposable income available to the person. Likewise for being connected to one's community and having enduring

and lasting relationships. *We are distinctly moving from quality of services to quality of life.*

In the psychiatric community notions of recovery and especially taking responsibility for one's own recovery have emerged as a high standard. This important aspect of self-determination needs to be promoted. However, the promotion of recovery and personal responsibility is or should be inseparable from support for living quality lives. If this notion of quality can be adopted and promoted for individuals with psychiatric disabilities then we will need to forge a public policy and financing agenda that will address the forced impoverishment of individuals with psychiatric disabilities, the homelessness of so many, the incarceration of many others and the inability to sacrifice meager federal benefits in the frequently vain hope that employment will eventually sustain the individual. Additionally, we will have to examine the low per capita investment that many states still make for this population.

What follows is a very modest attempt to initiate an agenda for quality lives that focuses on Medicaid, SSI/SSDI, Vocational Rehabilitation and the housing crisis that so many individuals with psychiatric disabilities face constantly. It is intended only as an initial formulation of public policy and financing strategies that hopefully will be generously augmented by the contribution of many others.

### **Funding a Quality Life**

From a public policy perspective it becomes important to articulate the costs of forced impoverishment and homelessness as well as the cost of marginal living arrangements that inhibit the assumption of responsibility for recovery. Studies are now beginning to emerge that demonstrate that it is wiser, e.g., to provide adequate housing for those previously homeless than it is to bear the public costs associated with continued homelessness. A recent seminal report on the difference in costs associated with continuing homelessness versus supported housing with a rich mix of supports in New York (Culhane, Meraux, and Hadley,

2001) revealed that, even after accounting for the costs associated with developing the housing, the increase in public costs was marginal.

The results:

A homeless person in New York City uses an average of \$40,449 of publicly funded services over the course of a year.

Supportive housing—independent housing linked to comprehensive health support and employment services—provides major reductions in costs incurred by homeless mentally ill people across the seven service systems--\$16,282 per person in a housing unit year round.

The reduction in service use pays for 95% of the costs of building, operating and providing services in supportive housing, and 90% of the costs of all types of service-enriched housing in New York City.

Accounting for all costs the marginal increase in total expenditures per person for the most common type of supportive housing was only \$995 annually.

This is not only better public policy it is good public policy. A precursor to a public policy and financing agenda should include a compilation of this type of research and an agenda for further research in order to better inform public policy.

It is in fact fairly intuitive to reason that safe, affordable housing and the potential for jobs and real income will bolster the possibility for successful recovery. What is needed is a cross-department national and state by state agenda that addresses the following issues:

- A comprehensive national and state policy on safe and affordable housing
- A model Social Security waiver that changes the disincentives within the SSI/SSDI program for individuals to work without jeopardizing benefits until income increases over current limits

- A model Medicaid waiver program specifically targeted to those with psychiatric disabilities that allows both services and supports as well as supplements to room and board
- A model vocational rehabilitation (including reform of The Ticket to Work) approach that targets cash grants to be deposited directly into individual accounts for job training and microenterprise development
- A National Public Policy and Financing Agenda

## **Housing: creating a national set of strategies for safe and affordable housing**

### **HUD and Public Housing Authorities**

HUD's only new construction/ Supportive Housing Program for people with disabilities, the Section 811 Program, has not only been drastically reduced in recent years, but also requires significant "up front" investment. Efforts to use the Section 811 program to develop the low-density housing that provides true community integration are particularly problematic.

Assuming that existing HUD programs represent, at best, a partial answer to the housing needs for individuals with significant disabilities, what can the psychiatric disability community propose as a supplemental program to meet the articulated needs of people with these disabilities? If we do not develop a supplement to HUD programs, do we believe 10 years from now we will have moved much further down the road of solving our housing crisis? Or, will most individuals with significant disabilities continue to have no options other than homelessness or marginal and unsafe housing?

If we are to adopt quality standards for housing based on universal human aspirations, then we need to dramatically increase housing assistance for individuals with disabilities in order to increase:

*The degree to which the person lives in typical housing;*

The degree to which the person chooses that home; and  
The degree to which the person chooses who lives with them

## **Recommendations**

These recommendations focus on 1) expanding rent subsidy programs to increase access to market rate rental properties and encourage landlord participation, and 2) developing a non-profit housing corporation infrastructure sensitive to the needs of individuals with psychiatric disabilities. (Rafter, 2003)

### **Rent Subsidy Expansion**

#### **Breaking Into Section 8 (Special Accommodations)**

Across the country most communities have lengthy Section 8 rent subsidy waiting lists or are not even accepting new applications because the waiting lists are so extensive. For many individuals with psychiatric disabilities the application process itself represents a significant barrier. After the Public Housing Authority's public notification that it is opening the application process, candidates must get to the Section 8 office, complete an application and have ancillary documentation such as bank statements, pay stubs, and social security cards. Even if the agencies supporting the individual with disabilities are aware of a sign up period, the necessary documents may not be readily available and application windows are missed.

In Columbus Ohio, *Creative Housing Inc.*, a non-profit housing corporation, showed the local PHA how the Section 8 sign up process unintentionally discriminated against individuals with significant disabilities. The local PHA designated Creative Housing as a "partner" and has initially assigned 180 project-based housing choice vouchers to Creative Housing for use for individuals with significant disabilities.

Creative Housing was able to assist the tenants in the application process and coordinate the collection of required documentation. These vouchers enabled

Creative Housing to attach a subsidy stream to 180 property units. Within this project, after the tenants live in the property for a year their voucher becomes portable and they can move and rent from any landlord willing to accept their voucher. In addition, if the tenants choose to leave, the Section 8 subsidy to the property is maintained. Creative Housing provides apartment-finding assistance to those individuals who prefer to use their vouchers to find housing elsewhere. The project enables a non-profit housing corporation to maintain a subsidy to units that have a waiting list of applicants while at the same time giving existing tenants the freedom to move on and rent from other landlords.

### **Supporting and Informing Public Housing Authorities (PHA's)**

Getting a local PHA to focus on providing housing for individuals with psychiatric disabilities is not readily accomplished and often requires a lengthy political and educational process. Partnering with a disability service group offers a PHA an efficient approach to provide housing services to people with significant disabilities. The Columbus, Ohio, PHA notes in its publications that partnering allows the PHA to:

- Target housing to the “neediest of the needy”
- Decrease the number of no-shows for applications and re-certifications
- Reduce the number of terminations for program violations
- Reduce landlord and neighbor complaints

In short, the partnership provides a mechanism for the PHA to target particularly needy individuals and also reduce their administration expenses. For disability organizations the Section 8 revenues represent a solid funding stream to support individuals who wish to reside in private market apartments. Section 8 can be an important funding stream for non-profit organizations that are developing housing, which requires deep subsidies for individuals with significant disabilities.

### **Creating a Subsidy Program in Each State**

Some states have taken the initiative to develop their own rent subsidy programs. Others, like Ohio, make bond dollars available to non profit housing corporations for purchase and renovation in order to create the deep subsidies that individuals on SSI need to obtain affordable housing. The strategy proposed in the Medicaid/SSI/SSDI section of this paper regarding the use of Social Security and Medicaid waiver funds to subsidize housing offers the possibility of expanding existing rent subsidy programs as well as initiating subsidies in those regions where they are non-existent. However as these subsidy programs are implemented it is necessary to build in funding flexibility to allow for the following:

**Bridge Subsidies with Section 8:** As access to Section 8 rent subsidies increases, it will still be a rare occurrence when waiver or state-only supports and Section 8 funding become simultaneously available to an individual. Regional or state subsidy funds can be used on a short-term basis with the understanding that the individual will apply for Section 8 subsidies, and when those funds are received the regional subsidy dollars will be used to support another individual.

**Deposit Assistance:** Many of the low-income individuals who will be served will not have enough money to pay the expected security deposits after other move-in expenses are incurred. Building in the flexibility to pay security deposits will be necessary.

**Extraordinary Damages:** There will be occasions when individuals in a subsidy program damage a property beyond their limited ability to compensate a landlord. Many apartments are under the umbrella of large property management companies, which have hundreds of units. The ability to “step up to the plate” and compensate a landlord for extraordinary damages will go a long way towards establishing successful partnerships with property management companies.

**Rent Payment Gap Funding:** Inevitably some individuals are either going to choose not to pay their rent or run into financial difficulties that prevents them from doing so. While some landlords may exhibit patience in this situation, others will move quickly to eviction proceedings. Once an individual has an eviction on their record they will typically be screened out of decent apartment communities and often relegated to substandard and unsafe housing. Creating the flexibility to



step into some situations and pay a tenant's portion of the rent can avoid an unwanted eviction.

### **Growing a Non-Profit Housing Infrastructure**

In *Priced Out in 2000: The Crisis Continues*, (Cooper & O'Hara, 2002) the most comprehensive national report of the housing crisis facing people with disabilities, the Consortium for Citizens with Disabilities (CCD) Housing Task Force recommended that efforts be made to strengthen the role and housing capacity of non-profit disability organizations. CCD is a Washington based coalition of approximately 100 consumer and advocacy groups, providers, and professional organizations who advocate with and on behalf of people with disabilities and their families TAC/CCD reports present a comprehensive overview of relevant housing programs that is extremely useful and does not need to be repeated here.

What does need to be stressed is that accessing these federal housing programs in a manner that is sensitive to the needs of the psychiatric disability community requires specialized expertise and up front funding. In short accessing these federal programs is beyond the capabilities of disability organizations that only dabble with housing on the side.

### **Creating Non-Profit Housing Corporations as a Catalyst for Change**

Non-Profit Housing Corporations are playing a central role where disability organizations have moved from a role of passive bystander to the housing crisis to an active participant in creating housing for people with disabilities. Such housing corporations serve as an important resource in assisting to put together a package for private market housing. They take the lead in implementing a housing development plan to serve individuals not readily served by the private market, and they become the center of concentrated housing expertise for serving people with disabilities including people with psychiatric disabilities. Successful non-profit housing corporations have several common characteristics:

1. Start Up Grants: Whether the corporation is founded from scratch or an existing low-income housing provider is persuaded to develop a disability sensitive focus, start up funds are needed. Management fees from rental properties primarily support staff salaries for the non-profit housing corporation. Initial start up grants serve to support the non-profit during an “incubation period” until the organization achieves a critical mass that allows management fees to support needed in house expertise.
2. Multi-Disability Focus: Housing corporations that have confined themselves to serving a restricted niche (e.g., housing for individuals with Down Syndrome) limit their growth potential and have minimal system wide impact. Successful organizations serve a broad cross section of disabilities, and have also included individuals with psychiatric disabilities and the elderly.
3. Work in Tandem with the Support System: Housing is separated from services and support, empowering people with disabilities to select and maintain services or supports separately. Necessary services are in place to support the tenants. Most important, guarantees of tenant-selected support services are in place before any development proceeds.

Housing development functions as a subset of an overall system plan, which is driven by stated customer preference and self-determination. Development of specific numbers of single-family homes, duplexes or apartments buildings occur as a result of an assessed need, with customers informing the system whether to emphasize developing single-family homes for shared living, or apartments for those who want to live alone.

Non-profit housing corporations are best positioned to work within the complex governmental funding and regulatory environment and produce the low rents needed to provide housing to individuals living primarily on Social Security. Moreover, non-profits are not going to convert properties to market rents once use restrictions have expired.

### **The Federal Medicaid Act and the Social Security SSI/SSDI Program**

The implementation of self-determination has been slowed and sometimes stymied by irrational aspects of both Medicaid and SSI/SSDI. There are prohibitions on room and board charges under Medicaid Waiver programs but in virtually no county in the United States is someone receiving SSI able to afford to live modestly and eat. The eligibility requirements of both programs force those who cannot jeopardize essential benefits to remain totally impoverished on a personal basis. Housing is often prohibitive and transportation unavailable. It is truly difficult to craft a meaningful life based on the principles of self-determination within the strictures of these two programs. Typical community support waivers are still not in place for most individuals with psychiatric disabilities.

### **SSI and SSDI**

The intersection of the SSI/SSDI, Medicaid and the Medicaid Waiver programs pose substantial problems for individuals with disabilities who rely on both. Supplemental Security Income (Title XVI of the Social Security Act) provides base cash income of \$530 a month. In 32 states eligibility for SSI based on limited income and disability automatically makes one eligible for Medicaid.

Some individuals become eligible for SSDI (Social Security Disability Insurance or Title II of the Social Security Act). This generates cash income based on having insured status as a worker or a child of a worker. The benefit under SSDI is an all or nothing proposition. If one becomes eligible then the full cash benefit

is calculated and the individual becomes eligible after 24 months for Medicare medical coverage—parts A and B.

The problem for individuals with any significant disabilities historically has been reluctance to “jeopardize” either one of these benefits by working and producing enough income to reduce or eliminate eligibility for these programs.

Under the SSDI program work incentives now include trial work periods, continued eligibility up to “substantial gainful employment”, extended period of eligibility, impairment related work expenses, extended coverage or purchase of Medicare and subsidy allowances.

Under the SSI program work incentives include continued SSI eligibility even when earnings exceed substantial gainful employment, continued Medicaid coverage, impairment related work expenses, PASS plans (plans to achieve self support) and student-earned income exclusions. Under both programs substantial gainful activity is \$810 (more if you are blind) but the standards for increasing income while reducing or eliminating benefits remain utterly complex for most individuals. This has led once again to the creation of a new job, not for people with disabilities, but for professionals called “benefits counseling”.

By all accounts these modifications are not working. More individuals with disabilities are not working or entering non-work programs today than enter the world of work and competitive or supported employment. Many who are enrolled in supported employment programs still earn below minimum wage and often work in segregated environments.

In virtually all counties and SMSA’s (standard metropolitan statistical areas) throughout the United States SSI income is not enough to purchase food and rent an apartment.

## **Medicaid Waivers**

Medicaid Waiver programs for individuals with disabilities cover support costs associated with living in community settings (though often in human service environments) and attending day, vocational or work programs. Unlike the Medicaid institutional program, to which it is an alternative, Medicaid Waivers are prohibited from covering the cost of room and board. Human service providers and people with disabilities are then forced to use most or all of their SSI or SSDI income for room and board costs. People with psychiatric disabilities typically do not enjoy long term care coverage under this program.

This frequently leads to congregate living arrangements in order to cover the costs of room and board and great caution in promoting anything that would jeopardize these payments. For those living at home where the family is low income these SSI and SSDI payments become very important for the financial stability of the family and family members will often counsel against the person working. Many individuals with psychiatric disabilities are forced into nursing homes, the streets or sub-standard housing.

Not adequately understanding the complex Social Security rules for working can also put individuals at risk of having to pay back income mistakenly accepted.

**Only by addressing directly the systemic problems in both the SSI/SSDI and Medicaid Waiver programs will the forced impoverishment of individuals be adequately addressed, regular housing opportunities made available and the ordinary freedoms associated with American Citizenship be obtainable for those with psychiatric disabilities. The following recommendations combine a waiver of some of the current rules under the SSI/SSDI program with an experimental 1115 waiver under the Medicaid program. While Medicaid acute care has become more available with earned income, long term care is still unavailable or inadequate. Section 1115 of the Medicaid statute allows prohibitions to be removed under a**

**controlled study of their effects. Also, it is suggested that a new provision in the Vocational rehabilitation Act (unlike The Ticket to Work) should be invoked to make small amounts of cash (through fiscal intermediaries) available to individuals in order to hire employment agents of their own or capitalize a microenterprise and obtain legislative changes to The Ticket to Work to accomplish the same.**

The underlying assumption of this approach is the achievement of better economic and housing outcomes for individuals with psychiatric disabilities. It would require the psychiatric disability community to petition both CMS (Centers for Medicaid and Medicare Services) and the Social Security Administration as well as each individual state government. These combined waivers simply provide incentives to work and live in ordinary ways—ways experienced by other non-disabled members of the community. They assume that any individual can generate private income based on creative job approaches through self-determination or the development of a microenterprise that the person may receive assistance in managing. Part of this assumption rests on the acknowledgement that we simply have to find more cost-effective supports without hurting individuals with disabilities. Because so few individuals with disabilities are working we simply don't know the contribution many could make to the costs of long-term supports and the potential positive impact on recovery.

Another assumption is that those enrolled in the 1115 Medicaid Waiver will automatically be enrolled in the SSI/SSDI Waiver governing income and asset limitations.

A final assumption is that with this increased flexibility individuals with disabilities and their close family and friends will achieve “better value” for the dollars available. With proper and unbiased assistance a new system of long term supports may emerge that removes the disincentives to work, allows for greater

flexibility in designing where and how one lives and demonstrates cost effectiveness.

## **THE NEW FREEDOM INITIATIVE**

### **Goals:**

- Secure a waiver under Social Security to allow for those interested in self-determination to increase their income and assets
- Secure an 1115 Medicaid Waiver that allows waiving some eligibility requirements and waiving those aspects of the Medicaid program that hinder living and working in the community for individuals with psychiatric disabilities
- Allow individuals to enroll in both the 1115 Medicaid Waiver and the proposed Social Security Waiver in order to encourage creative approaches to housing, work and meaningful lives
- Secure a waiver under the Rehabilitation Act including The Ticket to allow for cash grants
- Create a study to determine the cost effectiveness of this increased flexibility and reduction of disincentives to work while increasing opportunities to control transportation and achieve affordable housing
- Create a state-wide training and re-training effort to maximize the effectiveness of using all waivers simultaneously
- Create a model systems re-design for psychiatric disabilities that will be replicable across the country and prove cost effective

### **Purpose**

The Freedom Initiative is designed to demonstrate first, that when the current ceilings on income and asset limitations are raised, and Medicaid funds can be used more flexibly, individuals will overcome their resistance to earning money privately, take their place as ordinary citizens and resolve housing and transportation problems more efficiently. The second purpose is to demonstrate more cost efficiency in the use of public funds.

## **Social Security Waiver**

Written under the Social Security Act Section 1110(b)

Written to be utilized for those participants who can also enroll in the Medicaid 1115 Waiver for self-determination but especially as a stand-alone waiver for those with psychiatric disabilities.

## **Social Security Waiver Provisions**

1. \$1 reduction on *earned* income for every \$4-7 earned or a new threshold of \$500 is established *before* Social Security benefits are reduced.
2. \$1 reduction on *unearned* income for every \$4-7 generated
3. The establishment of *Freedom* accounts of up to \$10,000 per person
4. Continuing Disability Review *suspensions* for two groups participating

### **Provision 1**

- Participants take less of a reduction as earnings increase
- Waiver participant's cash benefits are reduced \$1 for every \$4-7 of earned income or they are allowed to keep \$500 before the reduction formula kicks in.
- The current system removes \$1 for every \$2 earned after the first \$85 is earned
- Participants keep much more of their earnings
- Participants start contributing to the Social Security Trust Fund

### **Provision 2**

- Certain types of unearned income receive the same \$1 reduction for every \$4-7 of unearned income (see also provision 3)
- Under the current system cash benefits are reduced \$1 for every \$1 of unearned income



- Unearned income can come from workers compensation, unemployment insurance, private disability insurance, state disability payments and private gifts and donations.
- This also encourages family members to save for their adult children with disabilities.

### **Provision 3**

- Participants can save up to \$10,000 per year of both earned and unearned income in a Freedom Account without affecting benefits
- Interest and dividends are not counted as assets
- Freedom accounts can become Individual Development Accounts or matched savings accounts
- Freedom Accounts can then be targeted for highly desirable personal goals including e.g., microenterprise development and expansion, down payments on homes and transportation, and additional training and educational opportunities as well as technology.
- Types of Freedom Accounts can be checking accounts, savings accounts, certificates of deposit, money market and mutual funds
- Freedom Accounts would be allowed even when the person is enrolled in an employer's retirement plan which would also be exempt from being counted as an asset
- Freedom accounts would allow family members to contribute to their children's future much as they do for their adult children without disabilities

### **Provision 4**

- Medical Continuing Disability Reviews would be suspended for two groups enrolled in the dual waivers: Medical Improvement not Expected (MINE) and Medical Improvement Possible (MIP)
- This provision addresses those who almost never leave the SSI rolls

There are a myriad of issues that would have to be addressed in accepting enrollment into this waiver including the effect on other benefits like food stamps and Section 8 housing certificates as well as anyone with a PASS plan. The proposal would also give those dis-enrolling or when the waiver terminates up to 24 months to “spend down”.

It is also possible for fiscal intermediaries to accept the reporting requirements under this waiver as well as the 1115 one. Together with a small research component the results can be tracked and disseminated on a regular basis.

### **The Second Waiver**

The 1115 demonstration waiver authority with the population of individuals with psychiatric disabilities has rarely if ever been used. This opportunity, now streamlined by CMS under the Independence Plus Waiver Template for all other individuals with disabilities, would allow a state to “waive” existing Medicaid provisions that hinder eligibility and meaningful lives for individuals with disabilities. As self-determination gets implemented under this waiver the essential “tools” of self-determination are implemented:

#### ***Fiscal Intermediaries***

#### ***Informed and Independent Support Coordination***

#### ***Individual Budgets***

The 1115 waiver can then accent those issues most problematic for individuals with disabilities and complement the Social Security waiver by addressing some of the issues associated with forced impoverishment by featuring the following exemptions:

- Waive the prohibition on room and board in order to make typical housing more available to individuals with disabilities

- Waive the prohibition on purchasing transportation including for those individuals who cannot drive but need to control the means of transportation to live meaningful lives
- Waive any exclusions to paying employers directly for co-worker support, training costs, transportation or temporary wage supplementation
- Waive all prohibitions on qualified Medicaid providers except where appropriate for normal criminal and other background checks. Allow individuals to contract with faith based groups as well
- Waive any real or perceived prohibitions on allowing individuals to capitalize very small microenterprises up to \$1500 annually

### **The Third Waiver**

#### **Vocational Rehabilitation Waiver**

Simply allow in each state small cash grants, funneled through a fiscal intermediary, to be available for individuals to hire anyone of their choosing to assist in securing a job or to use the cash to capitalize a microenterprise. This can begin to address the issues outlined above and begin to remedy the serious defects in the present vocational rehabilitation system most especially the Ticket to Work surrender of control after choosing a provider from a limited list and the requirement to abandon Social Security benefits under the Ticket. A legislative reform of the Ticket to work would move the tickets from vouchers to cash deposits with fiscal intermediaries utilizing individually controlled budgets and unbiased assistance in the production of income.

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# Getting to Systems That Promote Self-Determination Through Research and Evaluation

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## INTRODUCTION

Self-determination refers to individuals making life choices based on their personal preferences (Cook & Jonikas, 2002; Paulson, Post, Herinckx, & Risser, 2002; Nerney, 2001). These choices can be about a person's life, their interpersonal relationships, or the social roles they play. It is theorized that low-levels of self-determination among individuals with developmental disabilities and mental illness are frequently related to poor quality of life and limited societal involvement (Cook & Jonikas 2002; Johnson, 1999). Given this, it is importance to examine and understand the construct of self-determination and the processes that promote or hinder it.

Ideas related to self-determination first emerged as influential constructs in personality, humanistic, and social psychology in the 1960s (Rotter, 1966; Sheldon, Williams, & Joiner, 2003) and were embraced by the physical and developmental disabilities fields as a means of increasing the effectiveness and appropriateness of treatments. Self-determination for persons with physical and developmental disabilities might be viewed as the culmination of the normalization and deinstitutionalization movements that started in the early

1970s (Bradley, 1994; Algozzine, Browder, Karvonen, Test, & Wood, 2001).

Self-determination is now being introduced as a goal for persons with mental health problems (Cook & Jonikas, 2002).

We believe quantitative and qualitative research and evaluation can help us create systems that promote self-determination. In this paper, we will be referring primarily to quantitative research and evaluation. The paper considers challenges for quantitative research and evaluation posed by self-determination for persons with mental disorders. These challenges are in the areas of operationally defining and measuring self-determination, identifying services and practices that are effective in bringing about self-determination, and monitoring self-determination in report card oriented measures of quality assurance and consumer satisfaction efforts.

Most of the professional writing on self-determination has been devoted to position papers, conceptual work, and qualitative descriptions of promising programs (Algozzine et al., 2001, p.221). Establishing the values and conceptual basis of self-determination is important. It is also important to use quantitative research and evaluation to get to specific matters reflecting system performance, such as how many persons make how many choices in what life domains and how often these choices result in the actual attainment of goals and preferences (Nerney, 2001; Algozzine et al., 2001).

The qualitative research, evaluation, and performance measurement that can be found in professional writing focuses primarily on self-determination in persons with developmental disabilities. We will call upon this work in considering the challenges for quantitative research and evaluation on self-determination for persons with mental disorders. Trends in developmental disabilities suggest future directions for mental health self-determination research, evaluation, and performance monitoring.

The research and evaluation on recovery from mental disorders is another body of work related to the operational definition and measurement of self-determination for persons with mental disorders. Over time and through the efforts of consumers and advocates, the mental health field has come to understand that there is an outcome, recovery, that transcends symptom remission and functioning as previously understood (Cook and Jonikas, 2002). Ralph and others (Ralph, 2000; Ralph, Kidder, Phillips, 2000; Cook & Jonikas, 2002) have indicated that recovery is a complex outcome involving multiple concepts. Some of these concepts have meanings that are closely related to self-determination (e.g., empowerment); although others may be less closely related (e.g., hope, self-esteem, and spirituality). Similarly the Recovery Measurement Project (Onken, Dumont, Ridgeway, Dornan, & Ralph, , 2002) has developed self-report items to measure the degree to which services promote recovery that ask consumers how often their services honor their choices and preferences. Given this, we will cite work in the area of recovery in considering

next steps in research and evaluation on self-determination for persons with mental disorders.

## **OPERATIONALLY DEFINING AND MEASURING SELF-DETERMINATION**

The conceptual writings about self-determination suggest there are five aspects of self-determination to be measured. Two relate to self-determination as an outcome: (1) self-regulated, autonomous behavior (Algozzine et al., 2001) and (2) the attainment of a person's preferences in selected life domains (Agosta and Kimmich, 1997; Nerney, 2001). A third is the "combination of skills, knowledge, and beliefs that predispose and enable persons to engage in goal-directed, self-regulated, autonomous behavior (Field, Martin, Miller, Ward, & Wehmeyer, 1998, p.2)" (Algozzine et al., 2001, p.221). A fourth is the set of services and provider behaviors postulated to promote the outcome of self-determination. A fifth is the set of societal factors that promote self-determination.

The relationships between these variables are shown in Figure 1. Self-determination outcomes are caused by societal factors, predisposing person variables, and service and provider variables. Societal variables can also act indirectly on self-determination outcomes by creating an impact on predisposing person variables. Note, that personal characteristics also can influence what defines factors that promote self-determination at the societal and service levels. Note also, that we have connected societal factors and service and provider



factors. This is because mental health services related to self-determination are usually socially complex ones, involving multiple services and systems (Wolff, 2000). Wolf (2000) has described such services as having complex arrangements and soft boundaries.

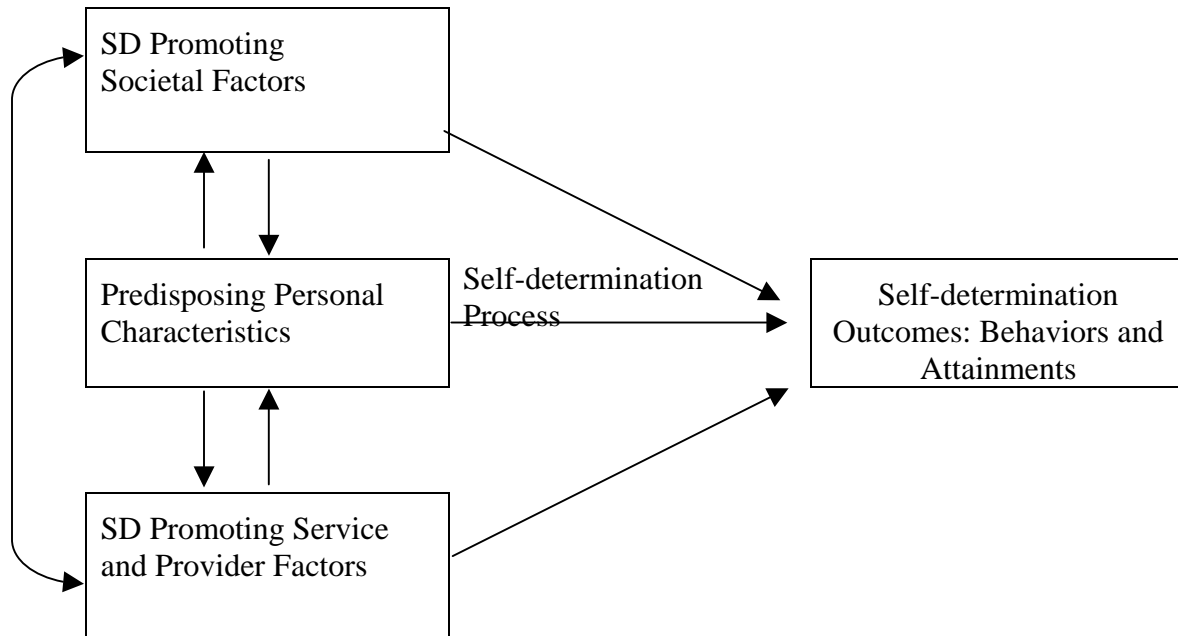


Figure 1. A Simple Logic Model Showing Factors That Affect Self-determination

**Self Determination Outcomes: Behaviors and Attainments.**

Psychometrically sound instruments have been developed for measuring self-determination for persons with developmental disabilities (Algozzine et al., 2001). Some examples include the Arc Self-Determination Scale (Wehmeyer, 1996) the Piers-Harris Self-Concept Scale (Algozzine et al., 2001); the National Core Indicators consumer survey (<http://www.hsri.org/nci/>) and the Life Choices Survey, (Kishi, Teelucksingh, Zollers, Park-Lee, & Meyer, 1988). There are also measures related to recovery that should bear upon self-determination. Ralph

(2000), for example, cites two: The Making Decisions Empowerment Scale (Rogers, Chamberlin, Ellison & Crean, 1997) and The Consumer Empowerment Scale (Segal, Silverman & Temkin, 1995). It is likely that a more systematic search for self-determination measures in the developmental disabilities and recovery literature would find more measures. The relationships among these measures need to be analyzed, both in terms of their content and in terms of the way measures relate when they are completed by the same persons to both explicate the nature of self-determination and specify its relationship to recovery.

We would like to make two more points about measuring self-determination that we believe may be important in thinking about how to measure this construct. First, as defined, self-determination appears to be about more than choice. It is also about having meaningful choices that relate to one's preferences or wants. It is not difficult to imagine situations in which people are given choices, but none are consistent with their wants or preferences. Based on our admittedly cursory review of instruments, at least some self-determination measures appear to measure choice, but not whether preferences are honored. It is one thing to ask, "Do you choose the agencies or providers that work with your family?" It is another to ask, "Do you choose the agencies or providers *you want* to work with your family?" A person who was able to choose among agencies or providers, none of which he or she wanted to work with his or her family, might answer yes to the former, but would have answered no to the latter. Self-determination, then, should be a function of the number of choices a person

can make weighted by the value to the person of the options chosen. In this framework, if you have many choices, but no options you value, you would have zero self-determination.

Second, it is likely that self-determination can be rated on a continuum, ranging from “not at all self-determining” to “completely self-determining”. It remains to be seen what an “ideal” score might be on such a continuum. As Cook and Jonikas (2002, p.5) note, most persons are “social beings, inextricably interlinked” [with others]. Although the integrity and autonomy of each human being is essential...there are dangers in defining personal freedom solely as the ability to make decisions that maximize personal benefit.” As Figure 2 suggests, from a quality of life perspective, the optimal amount of self-determination may not be the maximum amount.

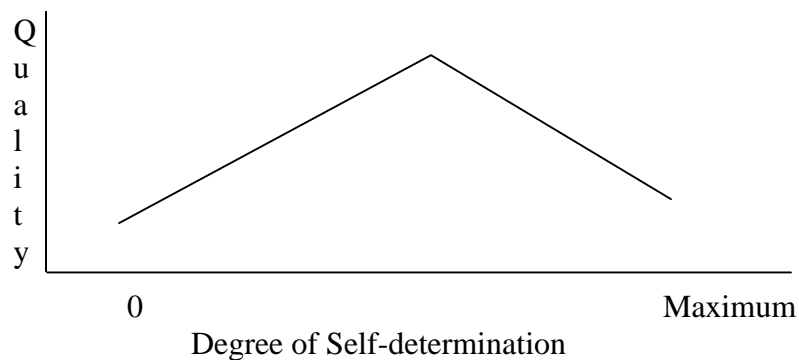


Figure 2. Possible Relationship Between Self-determination and Quality of Life

### **Predisposing Person Variables**

There are a number of personality attributes, skills, types of knowledge, and attitudes that have been postulated to predispose or enable persons to be

self-determining (Wehmeyer, 1999; Johnson, 1999). These include self-knowledge, choice making skills, self-observation skills, problem solving skills, positive attributions of efficacy and outcome expectancy, decision making skills, goal-setting skills, self-instruction skills, internal locus of control, and self awareness. It is postulated that many of these predisposing attributes can be taught in schools and services to increase self-determination (Wehmeyer & Schwartz, 1997; Algozzine et al., 2001).

It will greatly facilitate the development of curricula and practices that teach and inculcate these attributes if the various attributes can be operationally defined and measured. Then their inter-relationships and their relationships to self-determination can be studied. Such studies should give focus to curriculum development and practice improvement efforts. There exist a number of measures in personality psychology, social psychology, education, and recovery that pertain to these variables. These measures should be used as starting points for efforts to further refine ideas about predisposing person variables.

### **SD Promoting Societal Variables.**

There have been value-based and theoretical discussions of societal factors that promote self-determination for persons with developmental disabilities (Agosta and Kimmich, 1997; Nerney, 2001; Brotherson et al. 1995; UIC National Research & Training Center on Psychiatric Disability and the UIC NRTC Self-Determination Knowledge Development Workgroup, 2002). In mental

health, the literature has focused on societal factors that influence recovery and social re-integration (Cook & Jonikas 2002; Noordsy, Torrey, Mueser, Mead, O'Keefe, Fox, 2002).

A substantial portion of this literature has focused on reducing societal stigma – defined as negative societal beliefs about and reactions to persons with mental disorders (Onken et. al., 2002; Perlick, 2001). In a review of mental illness stigmatization, Perlick, Rosenheck, Clarkin, Sirey, Salahi, Struening, & Link (2001, p.1627) found studies showing that “employers, families of patients, mental health workers and prospective landlords all endorsed devaluing statements about or discriminated against mentally ill individuals.” Research has linked such perceived stigma in mental health with decreased self-esteem and adverse effects on social adaptation (Link, Struening, Neese-Todd, Asmussen, & Phelan, 2001; Perlick et. al., 2001), attributes that, as noted above, relate to self-determination. Interventions that reduce stigma should, therefore promote self-determination. However, we need studies of the effects of stigma reducing interventions on self-determination, specifically, to learn what types of interventions are best for this purpose. We say more about how the evidence about interventions should be developed below.

Policies, laws, and regulations about such things as the amounts and types of funding consumers receive (Nerney, 2001) and the use of coercive and restrictive interventions, ranging from court-ordered treatments to seclusion and restraint are other societal variables that effect self-determination (Cook &

Jonikas, 2001). Policy, legal, and regulatory interventions, such as advanced directives, that limit coercive interventions should expand self-determination. Proving that these interventions do so should be a high priority in the mental health field. Once again, we will discuss how the evidence for such interventions can be developed, below.

### **SD Promoting Service and Provider Practice Variables**

Many attributes of services and provider practices in systems have been postulated to relate to self-determination and traits that predispose persons to be self-determining for persons with developmental disabilities (Algozzine et al., 2001; Bradley & Agosta, 2001) and to recovery for persons with mental disorders (Cook and Jonikas, 2002). Methods employed to promote self-determination include large group instruction, individual conferences and one-to-one interventions of consumers (Algozzine et al., 2001). They also include interventions that change service models, financing arrangements, and provider attitudes (Algozzine et al., 2001; Nerney, 2001; Cook & Jonikas, 2002).

Interventions postulated to be effective in promoting self-determination are ones that encourage consumers to engage in self-advocacy and choice making and providers to support and respond positively to these behaviors. This is viewed as an ongoing process, throughout which an emphasis must be placed on providing opportunities for individuals to utilize acquired skills (Algozzine et al., 2001; Cook & Jonikas). In addition to promoting practices that achieve

desired outcomes interventions that promote self-determination discourage practices such as coercion and beliefs about competence, which inhibit consumer self-advocacy and choice (Unzicker, 1999; Cook & Jonikas, 2002).

Evidence linking specific types of interventions with self-determination outcomes is available in adult and adolescent developmental disabilities research (Algozzine et al., 2001), though there is little research on teaching self-determination skills to children and youth (citation\*\*). For example, Algozzine et al. found over 50 studies of interventions to promote one or more components of self-determination, 22 of which they were able to use in a meta-analysis.

However, there is a dearth of studies linking mental health interventions with recovery or self-determination (Anthony, 2001). We are at the beginning of research and evaluation on such interventions. In developing this evidence base it will be important to learn from previous experiences in identifying evidence-based practices.

## **IDENTIFYING SERVICES AND PRACTICES THAT ARE EFFECTIVE IN BRINGING ABOUT SELF-DETERMINATION IN SYSTEMS**

If self-determination is to become a driving force in influencing what mental health services and practices are developed, tested and disseminated in systems it will be important for it to be specified and measured as a key outcome in intervention research and evaluation. In making evidence-based interventions and practices that promote self-determination available to persons with mental disorders, it is useful to consider the steps that need to be taken. We briefly

describe these steps below. But before doing so, it is important to discuss several issues related to evidence-based practices, generally.

It is important to say that in a mental health system that promotes self-determination, it is important that consumers be involved in all of the steps listed below (Cook & Jonikas, 2002). It is also important to note that, contrary to what some people believe, developing evidence-based interventions does not necessarily eliminate consumer choice. Many evidence-based services and practices include consumer choice as a component. Paulson et al. (2002), for example, have recently described a version of Individual Placement and Support, an evidence-based practice, which incorporates choice as a fundamental component and includes process variables related to choice in the fidelity scale for the practice. Finally, having information about how different interventions facilitate consumer choice by produces a basis for informed decision making by consumers. This is the theory behind *Consumer Reports* and other efforts to help consumers make decisions.

Figure 3, shows the ladder of evidence in intervention science.

Intervention science is scientific principles applied to the specific task of bringing interventions that are proven safe and effective to consumers.





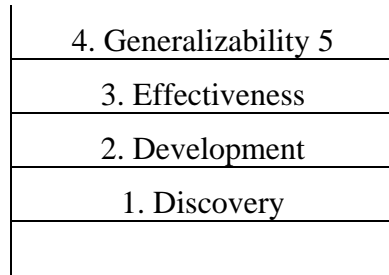


Figure 3. The Ladder of Evidence in Intervention Science

A first “discovery” step is to ask consumers and providers to identify services and practices that their experience tells them promote self-determination (“practice-based evidence”). A second is to develop those services and practices into replicable and scientifically testable interventions by describing them in a manner that enables others to implement them. This step also requires developing tools for testing such as fidelity measures to ensure that interventions are implemented as required and self-determination outcome measures. A third step is to compare self-determination outcomes for persons who receive such services and practices with those for comparable persons who do not. To accomplish this step, there should be multiple tests of an intervention by different providers and with different groups of consumers. This step is necessary because we have learned that interventions that are not tested in this way may not be as helpful as they seem or may even be dangerous (Unzicker, 1999). For interventions that pass step three, a fourth step is to test the generalizability of interventions to groups and settings that differ from the ones used to prove effectiveness. A fifth step is to develop and test materials and training to disseminate the intervention. And a last step is to develop tools to monitor the services and outcomes persons experience after the intervention has been

widely disseminated, to look for desirable or undesirable effects of the intervention that appear only with large scale, long -term implementation. Such monitoring efforts could be part of “report card” efforts to monitor service system quality.

A recent review of studies on interventions to promote self-determination for persons with developmental disabilities suggests that the research and evaluation in this area is mostly at step three in the process described above (Algozzine et al., 2001). Although this review does not clearly specify study designs, it does present data for studies that included control groups as well as single-subject studies. While some survey and evaluation tools exist of the type that could be used in Step 5 monitoring of self-determination, it does not appear that these tools are widely used to evaluate specific interventions that have been disseminated.

Within the mental health field there is a growing emphasis on what are referred to as evidence-based practices (Drake, Goldman, Leff, Lehman, Dixon, Mueser, Torrey, 2001); Leff, 2003). However, as noted above, there is limited research and evaluation about mental health services and practices that promote recovery and self-determination. As Anthony (2001) notes, “much of the existing, published, evidence-based practice research was conceived without an understanding of the recovery vision and/or implemented prior to the emergence of the recovery vision” (Anthony, 2001). Some research, for example, the

Consumer Operated Services Multisite Research Program (Consumer operated service program, 2002), is in the pipeline, but its results are as yet unknown.

Given the emphasis being placed on funding and disseminating evidence-based practices it will be critical for self-determination to become a key outcome measured when the evidence for interventions is being developed. Otherwise, policy makers, funders, and administrators will focus on interventions that are only indirectly related to self-determination, at best, or unrelated or a hindrance to it, at worst.

### **MONITORING SELF-DETERMINATION FOR QUALITY ASSURANCE “REPORT CARD” PURPOSES**

There is at least one “report card” project with instruments for monitoring self-determination for persons with developmental disabilities. The National Core Indicators Project (<http://www.hsri.org/nci/>) has questions on self-determination intended for families and consumers. Questions ask about choice in a number of areas ranging from choice of service provider, to choice of housing, and control over budgets.

There are also several nationally used instruments designed to measure consumer satisfaction in mental health for report card purposes that include questions about choice that bear on self-determination. These are the Mental Health Statistical Improvement System Consumer Survey and the Experiences of Care and Health Outcomes Survey (Eisen, Shaul, Leff, Stringfellow, Claridge, & Cleary, under review). These surveys both reflect interests in recovery by mental health stakeholders. For all the reasons cited above, we are certain that this

interest extends to and includes self-determination. However, from a research and evaluation perspective, we have work to do to operationally define and measure self-determination, expressly and decide on how this concept will be included in monitoring service system quality and consumer satisfaction.

## **AN AGENDA FOR RESEARCH AND EVALUATION ON SELF-DETERMINATION**

Self-determination is an important concept for persons with mental disorders. Work on self-determination for persons with developmental disabilities and on components of recovery for persons with mental disorder indicate that quantitative research and evaluation on self-determination can provide useful information for getting to systems that promote self-determination.

But research and evaluation work remains to be done.

We need to

1. Operationally define and develop measures of self-determination for persons with mental disorders. Measures developed should address not only choice, but also whether person's preferences are honored.
2. Identify, develop and disseminate services and practices that evidence shows directly contribute to self-determination in systems. These interventions should include ones that minimize the need for coercion in mental health treatment in any form.

3. Monitor self-determination in systems as a component of report card oriented quality assurance and consumer satisfaction. This should include measuring consumer experiences and systemic variables. The latter should indicate whether the necessary infrastructure for self-determination is in place. Such variables might include the presence of policies, regulations, and resources that reduce stigma and foster individual budgets, person-centered planning, the use of fiscal intermediaries, and the ability of individuals to change services and providers when they wish.

Pursuing the above agenda will require research and evaluation projects involving consumers, providers, policy makers and researchers and organizational support. SAMHSA's current science to services initiative is a step in the direction of having a federal agency and policies to provide this support. Under this initiative SAMHSA is expanding it's National Registry of Effective Programs (NREP), which currently includes substance abuse prevention services, to include mental health prevention and treatment services. The registry is accessible to all on the World Wide Web and each intervention listed is described along with the outcomes the intervention achieves. NREP uses intervention science guidelines, expressed as scorable criteria, to rate the quality of evidence for services that apply to be listed on NREP. Three raters functioning like peer reviewers rate applicants. Review teams do not now, but should be expanded to include consumers and other non-scientist stakeholders. Based on their scores, applicants are either not listed, listed as promising

services or listed as effective (evidence-based) services. Effective services with materials that make them disseminable are listed as model services. The plan is for services that desire to move up the evidence ladder to be given technical assistance and resources to conduct studies that address the intervention science guidelines. Thus the initiative promotes both science to services and services to science. Additionally, SAMHSA grant mechanisms are being redesigned to identify and develop services for NREP and use NREP to identify disseminable services. Finally, SAMHSA is working with other federal agencies like the National Institute of Mental Health and the Agency for Healthcare Research and Quality, states, and local agencies to pool resources for implementing this science to services agenda.

NREP and SAMHSA's broader science to services initiative provide mechanisms for identifying and disseminating interventions that promote self-determination. NREP reviews can explicitly assess whether interventions promote self-determination and SAMHSA's science to services initiative can mobilize organizational support from federal, state and local agencies for developing and disseminating interventions that are proven effective in achieving this goal.

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# Self-Determination and Person-Directed Support

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## **Introduction**

The national trend in long-term care policy and services has increasingly shifted toward models that emphasize person direction of services. The genesis of these models can be traced to the Housebound and Aid and Attendance Programs, operated by the Veteran's Administration for over 40 years (Cameron, 1993), and the independent living movement which, over the past 30 years, has promoted the development of personal assistance services for persons with physical disabilities (DeJong, Batavia, & McKnew, 1992).

The shift from institutional to community-based services has provided the first real opportunity for many adults with disabilities to make meaningful life choices and to access the services and supports they need. For example, as a result of changes in philosophy, advocacy, laws, and funding regulations, the number of institutionalized individuals with developmental disabilities has dramatically decreased over the past two decades (Braddock, Hemp, Parish, Westrich, & Park, 1998). Similar shifts have begun to occur, although more slowly, for individuals with psychiatric disabilities (Rothbard & Kuno, 1999) and for older adults.

Expanded access to person-directed, community-based services for individuals with disabilities has been facilitated by the Supreme Court ruling on *L.C. v. Olmstead* (1999) as well as by Department of Justice regulations that affirm the right of individuals with disabilities to be supported in the most integrated setting as required by Title II. of the Americans with Disabilities Act (ADA). Department of Justice regulations implementing this provision require that "a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities" 28C.F.R. 35.130(d).

Recommendations generated by the National Blue Ribbon Panel on Personal Assistance Services also called for the expansion of most integrated setting service options (Independent Living Research Utilization Program, 1999), and the Centers for Medicare and Medicaid Services, through its Real Choice Initiative, is supporting many state initiatives to expand home and community-based long-term services for people with diverse disabilities. Most recently, the report of the President's New Freedom Commission on Mental Health features "Goal 2: Mental Health Care is Customer and Family Driven", emphasizing the development of personalized, highly individualized health management programs that will help lead the way to appropriate treatment and supports that are oriented toward recovery and resilience. "Consumers, along with service providers, will actively participate in designing and developing the systems of care in which they are involved" (President's New Freedom Commission on Mental Health, 2003).

### **Philosophical Underpinnings of Person-Directed Services**

The philosophy of person direction recognizes the capacity of individuals to

"assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services they receive" (National Institute on Consumer-Directed Long-Term Services, p.4, 1996). The importance of personal control is validated by research showing a positive association between perceptions of control and quality of life for individuals with disabilities and elders (Hofland, 1988; Rodin, 1986), and other findings that link perceived control with health, disability and quality of life among elders (Salomon, Polivka, & Weber, 1998).

The emergence of person-directed service models is, in part, reflective of a societal shift from social benevolence toward people with disabilities to a growing acknowledgment of, and respect for, their capabilities, autonomy and personal rights (Powers, 1996). "Autonomy is understood as a cluster of notions including self-determination, freedom, independence, liberty of choice and action. In its most general terms, autonomy signifies control of decision-making and other activity by the individual. It refers to human agency free of outside intervention and interference" (Collopy, 1988, pp. 10). The growing focus on personal autonomy in long-term services has expanded the emphasis of care from the maintenance of health and safety to recognition of the roles of independence, reasonable accommodation and individual control of supports in facilitating quality outcomes.

In comparison to individuals with physical and sensory disabilities, this societal shift in perceptions and attitudes has been more subtle for older adults and for individuals of all ages with cognitive disabilities, who are often perceived as incompetent and helpless recipients of help (Scala & Mayberry, 1997). There also are significant concern among case managers regarding the perceived trade-off between autonomy

and safety (Micco, Hamilton, Martin, & McEwan, 1995; Scala, Mayberry, & Kunkel, 1996). Access to person-directed long-term services is, nonetheless, increasing among elders and adults with significant cognitive disabilities as the boundaries for the expression of autonomy have expanded to include supported decision-making and delegated decision-making by surrogates. Models are being developed that avoid the oversimplification that service users are either autonomous or non autonomous, permitting both collaborative direction of services by individuals and trusted others and delegated decision-making by surrogates.

**Person-direction of mental health services.** In comparison to other groups, significantly less progress has been made in advancing person-directed services for individuals with psychiatric disabilities (Cook & Jonikas, 2002). The evolution toward person-direction in mental health conflicts with traditional stereotypes of people with psychiatric disabilities as dangerous or malingering, unable or unwilling to take charge of their lives and requiring external intervention and control. From this perspective, self-determination is viewed as a privilege tied to adherence rather than as a fundamental human right.

Against this backdrop, mental health consumer / survivor leaders are calling for the end of forced institutionalization, intrusive therapies and medication. Leaders are advocating that personal assistance services be adapted and made accessible to individuals with psychiatric disabilities (Pita, Ellison, Kantor, 1999). They are working toward the expansion of empowerment service models, including consumer led drop-in centers, peer support and consumer-directed services (Fisher, 1998).

There is general agreement that responsive person-directed services should enable individuals to control services at the level they desire, and provide an array of supports that will maximize the customer's self-direction capabilities (Flanagan, Green, & Eustis, 1996; Scala & Mayberry, 1997). Such supports include giving individuals adequate information about service options, involving them in the service planning process, and providing resources and tools for customers to recruit, select, train and supervise their support providers (Eustis & Fischer, 1992). While effective approaches have been developed for involving individuals with physical disabilities to carry out these activities (e.g. Ulicny, Adler, Kennedy, & Jones, 1987), very little attention has been focused on providing mental health service users with such information and tools.

Furthermore, many mental health case managers, service providers and other mental health professionals have little background in the values of independent living, self-direction, personal assistance services, and ways to involve and support mental health consumers in service decision making and direction. There is a lack of understanding by some providers of the concepts of consumer choice, recovery, self-determination, and community integration, and many professionals have therapeutic rather than service coordination backgrounds. Thus, mental health professionals often do not have the orientation, knowledge or experience necessary for promoting the capacity of individuals to self-direct or to hire others to assist with activities as a method for recovery.

Researchers and policy leaders have identified as a key barrier to the utilization of person-directed services the beliefs by many mental health professionals in a "therapeutic" paradigm of services, in which their primary role is as therapist (Ellison,



Rogers, Sciarappa, Cohen, Forbess, 1995). Pita, Ellison, Farkas, & Bleeker, (2001), in reporting the results of their survey of State Mental Health Directors stated, "the majority of states viewed psychiatric personal assistance as an element of psycho-social rehabilitation rather than seeing it belonging to an independent living framework".

### **Models of Person-Directed Services**

Person-directed models of long-term services across disability and age groups generally emphasize the following elements (DeJong, Batavia, & McKnew, 1992; Kane, 1996; Fenton, Entrikin, Morrill, Marburg, Shumway, & Nerney, 1997; Scala & Mayberry, 1997):

- (a) the authority and accountability of the service customer;
- (b) individualized, customer-directed service planning;
- (c) customer selection, training and supervision of support providers;
- (d) limited oversight by medical providers;
- (e) flexible benefits that include personal assistance, assistive devices, environmental modifications, customer education, support brokers, fiscal intermediary and employment supports;
- (f) individualized funding of service plans through cash payments to customers or customer authorization of service payments by a funding agency or fiscal intermediary; and
- (g) customer definition and monitoring of service quality.

Typically, the language used to describe person-direction of services varies across the disability community. Many people from the independent living community emphasize "consumer control" and associate it with the management of personal

assistance or attendant services. In developmental disabilities, person-directed services are most often referred to as "self-determined or self-directed services". Among elders, the person-direction discourse is less well defined and may be referenced to autonomy or consumer-directed services". Terms used in the mental health and psychiatric survivor community may include "empowerment, liberation, peer-run services, and self-determination". For the purposes of our discussion, individuals who use person-directed services are referred to as "customers" unless a source is being cited that used another reference term.

A 1999 survey by the National Council on the Aging identified 185 person-directed programs throughout the United States (Velgouse & Dize, 2000). The majority of the programs served customers of all ages although services for persons with developmental disabilities and younger people with disabilities predominated. Several new person-directed, long-term service model demonstration initiatives have emerged, focused on people with diverse disabilities and elders (Mahoney, Simone, & Simon-Rusinowitz, 2000; Moseley, 2001). Many of these initiatives are specifically aimed at identifying and addressing federal and state barriers to person-directed, long-term care services.

### **Structure of Person-Directed Service Models**

Models of person-directed services can be designed to provide for varying levels of control, including (a) direct cash payments and counseling for individuals who are responsible for all facets of funding and service management, (b) fiscal intermediary programs that assume responsibility for administrative employment functions (i.e. payroll, taxes, paperwork) while customers manage their services, (c) supportive

intermediary programs that assist customers with activities such as service coordination, brokering supports or screening and training care providers, (d) self-directed case management programs which actively involve customers in decisions regarding their services, but retain control over the management of funds and services, and (e) spectrum service programs in which customers can choose among a range of the above support options (Flanagan, Green, & Eustis, 1996). Most person-directed programs offer customers only one of these options rather than a range of supports (Scala & Mayberry, 1997). Where there is a choice of services, it is typically between programs that provide cash payments and leave all service management to customers or programs that allow customers to designate all of their service management to an agency. In some cases, support is available from an agency that assists customers with administrative employment tasks (e.g. payroll issues). Three of the most dominant types of person-directed services are personal assistance services, brokered support and Cash and Counseling.

**Personal assistance services.** Historically, much of the attention in the design of person directed services has focused on the delivery of personal assistance services. Personal assistance services refer to assistance with tasks that individuals would normally do for themselves if they did not have a disability (Litvak, Zukas, & Heumann, 1987). Such services include personal care, ADL's, IADL's, communication supports, paramedical services (e.g., medication administration, catheterization, injections, ventilator care), home modifications, assistive devices, and service coordination (Doty, Kasper, & Litvak, 1996).

Among adults with physical disabilities, personal assistance services are most commonly provided through Medicaid personal care programs whereas within aging and developmental disabilities services, these services are more commonly supported through Medicaid home and community-based long-term care services waivers (HCBS) (Scala & Mayberry, 1997). Most programs that fund personal assistance services emphasize in-home services delivered by providers (e.g., attendants or personal assistants), in contrast to the broad spectrum of supports included in the above definition. Many programs also provide fiscal intermediary services and assist customers with administrative employment tasks. Although, programs that provide customer-directed personal assistance services exist in a majority of states, most are small demonstrations or, as a function of restricted funding, they are accessible to a limited number of participants.

Clearly, the major advantages of person-directed personal assistance services are the individual's control over the selection and direction of his or her personal assistant(s) and the fairly flexible, functional ways in which a personal assistant can be used. Historic challenges in these programs have been their narrow definition of services, focusing on in-home supports delivered by a provider, such as personal care, homemaking and other physical tasks that, although essential for persons with physical disabilities, may not be relevant for persons with cognitive or psychiatric disabilities. For example, users with psychiatric or cognitive disabilities may desire personal assistance to carryout homemaking activities, to make appointments, to access employment, recreational and social opportunities in the community, to manage medications, or to plan and organize activities. Although formal program eligibility requirements may

include all persons with disabilities, program service definitions may focus on the needs of persons with particular functional challenges.

A second challenge for many personal assistance service programs is a lack of information available for personal assistants and customers related to effective practices and tools for hiring, training, supervising, evaluating and firing assistants. Many person-directed personal assistance programs have struggled with reconciling their commitment to ensuring the autonomy of customers in directing their supports with the need to provide customers with information and tools that will enable them to be successful employers. Programs that limit their involvement to providing fiscal intermediary and employment supports for customers also are reluctant to become involved in customer or personal assistant education because of liability concerns. Personal assistance programs administered by independent living centers often offer peer-based support to assist customers in this area.

**Brokered support.** Brokered support is a model of self-determination-based service that has been primarily utilized with customers who have developmental disabilities, although small demonstrations are underway with other disability groups, such as the pilot brokerage being developed for individuals with psychiatric disabilities in Oregon through its Real Choice Project. Brokered support focuses on assisting customers, as they choose, to accomplish the following seven functions:

- a. Self-define their goals for life and plans to achieve them.
- b. Access opportunities, resources and supports that enable them to achieve their goals.
- c. Expand the range of employment, housing, recreational and other

opportunities and supports available through community development and networking activities.

- d. Access information and education that increases their capacities to make informed decisions, to achieve their self-defined life goals, and to direct their supports.
- e. Pay bills, negotiate contracts, etc. that are necessary to carry out their plans.
- f. Do employment paperwork, background checks, and hiring, training and supervision of the people they choose to support them.
- g. Monitor their achievement of plan goals and the quality of their supports, and to make adjustments, as desired.

Brokered support typically involves making available to customers a broker, personal agent, or coach who functions as an ally for the customer, having a primary commitment to supporting the individual to achieve his or her life goals, including determining and directing supports that are needed. It is important that the broker does not have other roles that may potentially conflict with his or her primary allegiance to the customer, such as a case manager who is also responsible for eligibility and protective services decisions, or a service provider that could be impacted by the customer's choices. Brokered support can be delivered by independent agents that customers select or by staff of brokerage organizations dedicated to providing brokered supports. Brokers may be involved with customers for limited or ongoing time periods.

Brokered support typically combines the availability of a broker with flexible funds that customers can allocate to achieve their goals, as reflected in their individualized service plan. Funds are generally assigned to the customer and held in an account

rather than given as cash. Brokered support programs typically provide fiscal intermediary services and assist customers with administrative employment tasks. Customers remain the employers of record. Customer use of flexible funds is typically defined as a function of the services included in the state's Medicaid HCBS waiver: Many states are striving to include a variety of waiver services that respond to the individualized needs of customers, however health and safety outcomes, which serve as the basis for the HCBS program, present some inherent limitations to the inclusion of some individualized supports.

Brokered support models, combining a broker with individualized funds, clearly provide a greater level of flexibility and control for the customer than do traditional "menu" based approaches. A major advantage of brokered support from an independent broker is the customer's ability to select the broker, while a disadvantage can be lack of broker expertise and training. Brokerage organizations are more easily able to train and support brokers and to provide fiscal intermediary supports than are independent brokers. However, customers of brokerage organizations may not be permitted to choose their brokers and these organizations are vulnerable to devolving into beauracratc entities that loose their flexibility to respond to individual customer needs as they institute policies, procedures and support menus that guide their work across customers and that ensure their organizational stability. If brokers have ongoing responsibility for monitoring or remaining in the lives of their customers for some reason apart from that requested by the customer, they also risk compromising their commitment to customer autonomy.

**Cash and Counseling.** Cash and Counseling demonstrations have been formally underway in Florida, Arkansas and New Jersey, and piloted in other states through Independent Choices or other initiatives. These demonstrations have involved customers with physical and developmental disabilities and elders. Customers with primary psychiatric disabilities have, for the most part, not been included.

Cash and Counseling programs offer a financial allowance instead of disability-related supportive services (Phillips, Mahoney, Simon-Rusinovitz, Schore, Barrett, Ditto, Reimers, & Doty, 2003). Customers cash out their Medicaid personal care or HCBS service benefit to pay for allowable disability-related goods and services that are included in their spending plans. Expenditures can include small amounts for incidental expenses paid in cash by the customer, such as taxi fare or ordering a pizza (rather than paying a service provider to do meal preparation), in addition to service provider payments and invoices for items such as adaptations and equipment. In most cases, fiscal intermediary and employment assistance is offered, however customers that demonstrate the ability to perform these activities are allowed to do so. Fiscal and counseling supports are provided by case managers, provider agencies and independent support coordination organizations.

Cash and Counseling generally offers the highest level of autonomy and flexibility to customers and is attractive to those individuals that desire to have authority and responsibility for their services. Findings from the Cash and Counseling demonstration (Phillips, et al, 2003) indicate that customers use the majority of their funds to pay providers, who are often family members and acquaintances. Many customers elect to have family members or close friends assist them in managing their allowance and



services. Most customers also use fiscal intermediary services if they are provided at little direct expense.

Cash and Counseling programs, like support broker models, risk having conflict of interest problems when counseling is provided by agencies that also offer traditional services. Providing adequate support and supervision for part-time counselors is also difficult. Finally, because customers often hire family members and acquaintances, those without family and friendship connections are likely to require additional support to find workers.

## **Summary**

Personal assistance services, brokered support and Cash and Counseling models are primary examples of person-directed services being offered to increasingly more customers each year. Each model emphasizes customer control and individualized supports; offering different elements with utility for customers with diverse needs. Although each model expands the range of services and supports available to customers, all share some constraints as a function of funding source and local resources, standards and attitudes.

## **Evaluation of Person-Directed Service Models**

Person-directed service models have a brief history as compared to traditional institutional and home care models. Studies conducted to evaluate the efficacy of person-directed services are highly variable in their methodological rigor. However, taken as a whole, findings to date suggest that person-direction of services may have benefits for a significant proportion of individuals. Several national and international studies have specifically evaluated the impact of person-directed models on factors

such as quality of life, control, productivity, use of preventative health care and cost.

The oldest person-directed service benefits are the Housebound and Aid and Attendance Programs, operated by the Veteran's Administration (Cameron, 1993). Over 200,000 veterans and surviving spouses receive cash benefits in place of formally provided homemaker, personal care and other services. Funds may be spent on whatever the customer believes is most necessary to meet his or her health and personal needs. An evaluation of these programs, conducted by Grana and Yamashiro (1987), suggested that the participants received similar hours of care and they were not worse off with regard to acute health care utilization than a comparison group.

Several other studies of person-directed services have focused on the evaluation of personal care programs. For example, a 1993 Louis Harris Poll of 800 persons receiving person-directed personal care services through Medicaid revealed that persons who hired independent, as opposed to agency, providers reported higher levels of satisfaction with their care, provider stability, and quality of life (Harris & Associates, 1993). An evaluation of the impact of person-directed personal assistance in Virginia compared the outcomes of a small number of individuals receiving person-directed personal care services with those on the wait list for such services (Beatty, Adams, & O'Day, in press). Person-directed services included funding for personal care from an individual hired and supervised by the customer as well as assistive technology, home modifications, and adaptive equipment. Use of consumer-directed personal care services were associated with higher levels of control over life, satisfaction with services, control over services and availability of services (Beatty, Richmond, Tepper, & DeJong, 1998), productivity and employment (Richmond, Beatty, Tepper, & DeJong,

1997), and utilization of preventative health care (Adams & Beatty, 1998).

Similar findings were obtained from a study comparing agency-directed and person-directed services for individuals with developmental disabilities. The recipients of person-directed services demonstrated significant increases in their control over decisions and quality of life. Customer-directed services were also provided at a 12% cost savings (Conroy & Yuskauskas, 1996). In their subsequent study of customer outcomes associated with participation in a Robert Wood Johnson Foundation funded self-determination initiative, Conroy, Fullerton, Brown and Garrow (2002) obtained pre and post participation data for 800 individuals in nine states. Their findings indicated that participants shifted much of their care from professionals to family and friends. Participants and those closest to them reported significant improvements in participant quality of life in all 14 life areas examined. Finally, the cost of customer participation in self-determination-based services was lower than a comparison group of individuals receiving traditional services.

Benjamin, Matthias, Franke, Mills, Hasenfeld, Matras, Park, Stoddard, & Kraus, (1998) conducted an interview study of 1,095 users of consumer-directed and professionally-directed personal care programs in California. Approximately one-half of the users of consumer-directed services were age 65 or over and 52% had severe physical disabilities in comparison to 13% of the users of professionally-directed services. The users of consumer-directed services reported significantly higher levels of empowerment over their services, satisfaction with both the technical and interpersonal aspects of their services, service quality, and emotional, social and physical well-being than did the users of professionally-directed services. They also

reported significantly higher levels of safety with their assistants, assurance of back-up assistance, and ease of arranging services, as well as lower levels of unmet needs.

Tilly and Bectel (1999) reviewed Benjamin's study and 4 additional studies of consumer-directed cash payment service models in Austria (Badelt, Holzmann-Jenkins, Matul, & Osterle, 1997), Germany (Runde, Giese, Kerschke-Risch, Scholz, & Wiegel, 1996), the Netherlands (Miltenburg, Ramakers, & Mensink, 1996) and France (Gilles, Groc, Legros, 1995; Simon & Martin, 1996). They concluded that the receipt of cash subsidies were associated with enhanced perceptions of control over services and supports, made it possible to compensate relatives for care and to purchase more services, and promoted overall quality of life. They suggested that agency and direct payment options should be broadly available to customers in conjunction with a range of supports for those customers who choose self-directed services.

The study of care in the Netherlands (Miltenburg, Ramakers, & Mensink, 1996), a rare experimental evaluation of the impact of choice between agency services and cash subsidies, involved the random assignment of 1,066 recipients to one experimental group that permitted a choice of cash or agency services, to a second experimental group that permitted a choice of cash, cash and counseling or agency services, or to a control group that provided agency services. Forty-five percent of the participants in each experimental group chose the cash benefit, while only 7% of those who chose cash also chose counseling. Thirty percent of the participants over age 75 chose the cash benefit. Participants who choose cash in the experimental groups were significantly more likely to report that their helpers were efficient, they received greater continuity of care, they had more choice and control over their services, and they were

able to purchase more hours of service, than were the participants in the agency services group. Ninety percent of the participants indicated they would chose the cash option again. Most of the cash subsidies were used to purchase services and 80% of the participants reported no difficulty obtaining services.

The Cash and Counseling initiative currently underway in the U.S. is yielding some findings related to the impact of services on participants that have been randomly assigned to receive either cash payments or traditional services (Foster, Brown, Carlson, Phillips, & Schore, 2001; Foster, Brown, Phillips, Schore, & Carlson, 2003). Results available from Arkansas suggest that disability-related health outcomes were at least as good as those for control group participants, and Cash and Counseling participants were less likely to report unmet needs and more likely to report satisfaction with their supportive services, compared to control group participants. Over 85% of the cash payment participants indicated they would recommend the program to others.

These findings suggest that, where there is a choice between direct cash payments and agency services or a fixed type of service, many people prefer direct payments. One of the major benefits of direct payments is the flexible funding of support provided by already existing family and other informal caregivers. However, a significant percentage of recipients, particularly those who are over 80 years old and/or who desire assistance to manage their supports, may elect agency services.

Several studies have found that the users of person-directed services were able to obtain more hours of service than were the users of agency services (Benjamin et al, 1998; Egley, 1994; Feinberg & Whitlatch, 1997; Miltenburg, Ramakers, & Mensink, 1996). All but Egley (1994) attributed this finding to lower hourly wages and the

provision of more unpaid hours of service by person-directed service providers. Egley (1994) found that the cost saving was due to reduced administrative costs rather than lower wages and benefits for providers. Although reduced costs associated with increased hours of service are a positive outcome from a customer's perspective, this finding raises questions regarding the status of independent care providers that is being shaped by through the wage parameters established by person-directed service programs.

### **Barriers to Person-Directed Support for Individuals with Psychiatric Disabilities**

The lack of access to person-directed support by customers with psychiatric disabilities is striking and suggests that they have been left out for reasons other than that they would not benefit from such supports. The lack of access by customers with psychiatric disabilities appears most related to their participation in separate service systems that are not linked to those available to individuals with other disabilities or elders, and to a general lag in service evolution within the mental health system. Attention to the potential benefits of using person-directed approaches may also be overshadowed by the increasing emphasis in mental health on the adoption of "effective practices" such as family psycho-education, supported employment, dialectical behavior therapy (Drake, Goldman, Leff, Lehman, Dixon, Mueser, & Torrey, 2001). These practices have been specifically developed and validated by mental health professionals, aimed at addressing specific medical and psychosocial outcomes for persons with psychiatric disability (e.g., decreased hospitalization, social adjustment, family stress and burden, behavior symptomatology, employment, and medical care costs).

Person-directed support models provide validated approaches for assisting individuals to determine and direct their support. By definition, they do not prescribe specific supports that are appropriate for any individual or group. Rather, they provide methods for customers and their trusted allies to identify those supports that individuals need to optimally promote their recovery, health and quality of life. It is likely that access to practices documented as effective for persons with psychiatric disabilities, and perceived to be of benefit by customers, will be selected by individuals as components of their personalized support plans. Thus, using person-directed support approaches and making effective practices available for customers to select are complementary aspects of developing a holistic, person-centered system of support. There is a pressing need to more clearly understand how individuals with psychiatric disabilities can benefit from accessing person-directed services as well to identify the most empowering and efficient ways to provide such supports.

### **Discussion**

Person-directed services are currently not accessible to most individuals in the mental health system. Increasing the number and scope of person-directed service models accessible to individuals with psychiatric disabilities will likely require further validation of their benefits, policy and system improvements that address the barriers to person-directed services, ongoing consumer / survivor advocacy and the strengthening of political will necessary to divert increased funds toward community-based, person-directed services.

Studies should be undertaken to investigate the types of person-direction supports needed by persons with psychiatric disability, the relative benefits of different

service models, and the organizational configuration of person-directed support programs. Collaboration between consumer /survivor advocacy organizations, mental health professionals, researchers and other long-term care stakeholders will be critical for increasing access to person-directed services. Research must focus on gathering evidence regarding the efficacy of person-directed approaches for promoting recovery from a holistic perspective with consumer /survivors actively involved in all facets of the process.

Research and thoughtful planning should take place to further investigate and promote the effectiveness of person-directed services. However, individuals with psychiatric disabilities should not have to wait for 10 or 20 years to gain the right to determine their services until professionals have conducted a multitude of demonstration and research projects. As Hagner (1996) wrote, "Historically, in education, housing, employment, leisure, and other domains, we as a field began with very restrictive, oppressive ways of treating people with disabilities, and have been engaged in a massive, decades-long effort to lighten up. That is true historically, and each less intrusive "newcomer" has been greeted with suspicion and requests for proof, but it is not true conceptually or morally. Conceptually and morally, the presumption has always been in the opposite direction. It is the unnatural supports that are on trial (p. 183)".



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**UIC NRTC 2003 NATIONAL  
SELF-DETERMINATION &  
PSYCHIATRIC DISABILITY CONFERENCE:**

**TRACK #3 PAPERS**

**SOCIETAL/COLLECTIVE  
SELF-DETERMINATION**



# Barriers to Self-Determination for People Who Have Been Identified as Having Mental Illness in Western Society

*By Pat Risser, B.A.*

EBAY  
mental patient  
costume  
Item number:  
2948293469



## Introduction

Self-determination is the ability to make informed choices for one's own life with a reasonable expectation of hope for the future. Self-determination means being in

charge of your own life, having the resources you need to create a good life, making responsible decisions that are best for you and for others around you, and choosing where, when, and how you will get support and assistance for your mental and physical health problems.

These broad definitions don't fully address the specific and unique issues of people who have been psychiatrically labeled. Just as some have made strides in securing rights for people in the disabilities rights movement, other people are speaking out in the psychiatric consumer/ movement saying, "We want our voice respected and heard. We don't just want a seat at the table, we want to be the primary voice at the table!" The psychiatric consumer/survivor movement has gone so far as to borrow the saying, "Nothing about me without me" from the disability rights movement.

There are many barriers to self-determination for people with psychiatric disabilities/labels. Some of those barriers such as self-doubt are generated internally within the person. Some of those barriers are created by the treatment system itself. Other barriers are imposed by our society. This paper will address some of those societal barriers.

On April 29, 2002 President George W. Bush announced the creation of the President's New Freedom Commission on Mental Health at the University of New Mexico in Albuquerque. In his address, the President identified obstacles to quality mental health care. One such obstacle is the stigma that surrounds mental illness, "a stigma caused by a history of misunderstanding, fear and embarrassment."

Stigma and discrimination are commonly mentioned as barriers to self-determination. These are terms that reflect attitudes and practices in the way people are treated. To some extent, language itself expresses a type of

discrimination however; more important are the thoughts, feelings and attitudes that are triggered in others when people use certain words in describing people with psychiatric disabilities/labels. There is a historical prejudice against “those” people, the nuts, the crazies, the insane, the retarded, etc.

[From the Oxford Thesaurus]

mad, insane, demented, deranged, unbalanced, unhinged, lunatic, non compos mentis, daft, certifiable, mental, touched (in the head), out of one's mind or head, mad as a March hare or hatter, maddened, crazed, barmy or balmy, cuckoo, cracked, crackers, crack-brained, dotty, daffy, dippy, gaga, goofy, crackpot, loony, off one's rocker, have a screw loose, screwy, batty, bats, bats in the belfry, barmy (in the crumpet), potty, bonkers, round the bend or twist, off one's chump, doolally, off one's trolley, out of one's gourd, screwball, nuts, nutty (as a fruit cake), bananas, out to lunch, meshuga, flaky, flaked-out, (plumb) loco, crazy, silly, absurd, foolish, nonsensical, inane, ridiculous, preposterous, laughable, risible, ludicrous, asinine, stupid, moronic, imbecile or imbecilic, idiotic, feeble-minded, hare-brained, crackpot, impractical, impracticable, unworkable, unsound, pointless, imprudent, rash, reckless, ill-considered, zealous, wild, maniac, mental patients, mentally diseased, neurotic, psycho, psychotic, schizophrenic, unsound mind

Further stigma occurs when our whole social system participates in discrimination via the naming of laws after sensationalized and isolated tragedies. Kendra’s Law in New York, Laura’s Law in California and Brian’s Law in Ontario, Canada are examples of the larger social discrimination against people who have been psychiatrically labeled. These laws are all designed to expand the ability of the mental health system to forcibly “treat” people. However, at the same time, these laws erode the rights of many other people. There should not be a single model of treatment applied to everyone – “for every story.”

### Barriers to Self-determination and Recovery within American Society

We commonly speak of people who suffer from or struggle with mental illness. Words like “suffering” and “struggling” have a negative tone, reinforce

stereotypes, evoke pity and may even set up “self-fulfilling prophecies” for people with psychiatric disabilities/labels. They may also help to perpetuate some of the myths that exist regarding “mental illness.”

A recent search of the worldwide web on the Internet yielded almost 25,000 results when searching for “myths mental illness.” A sampling of the first 100 of those results found over 75 instances where people who had been psychiatrically labeled were described as “suffering” or “struggling.” From this sampling, it would appear that even those who are allegedly working to dispel myths are actually perpetuating myths! Many people who have been psychiatrically labeled are not suffering or struggling. Many are focused on hope, on recovery or on becoming more self-determining. Even those who may feel they are suffering or struggling do not suffer or struggle all the time.

To refer to someone as a victim of mental illness, suffering with or afflicted by a mental illness sensationalizes the issue. One person reports that he missed hearing his “voices” when he took psychiatric drugs. In fact, he stopped taking the psychiatric drugs and said he felt sorry for the rest of us because he never realized how truly alone we are until he stopped hearing his “voices.” He is one example of someone not suffering.

"Although the world is full of suffering...it is also full of overcoming it." -- Helen Keller
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Part of the problem with our language is that we lack a common definition to the term “mental illness.” Current models that describe “mental illness” all look at behaviors to describe a deviance from prevailing social and cultural standards. These models all differ in their explanation of the causal effects of “mental illness.” The medical model believes that “mental illness” is either a physiological disorder of the brain chemistry or else an inherited problem rooted in faulty genes (although perhaps amplified by environmental factors). Under this model, the

“cure” would be to restore the mysterious balance of the chemistry of the brain or else to pursue genetic engineering to stop the proliferation of this “disorder.”

The spiritual model of “mental illness” believes that differing behaviors are basically a discomposure of the “soul” and that relief for this discomposure is to be found through a mysterious balancing of the psyche and the environment.

The functional model believes that “mental illnesses” are deviations of proper, statistically “normal” behaviors and is therefore, an unhealthy sickness. This “sickness” is repaired when a person is rendered “functional” again within the statistically “normal” culture.

All of the above models infer the source and definition of “mental illness” from the success or failure of their treatment modalities rather than from an a priori causality. The result is a confusing cacophony of claims about “mental illness” and a constantly changing list of diagnoses with little internal consistency.

“Neurosis, a historically fundamental "condition" vanished after 1980. Homosexuality, according to the American Psychiatric Association, was a pathology prior to 1973. Seven years later, narcissism was declared a "personality disorder", almost seven decades after it was first described by Freud.” Sam Vaknin “Myth of Mental Illness”

One fairly common myth is that a diagnosis of mental illness means that a person is incapable in all areas of their life. Imagine the hundreds of thousands of decisions you make every day. You decide when to get up, whether to hit the snooze alarm, once or twice, what to wear, whether to go to the bathroom now or after your boss has finished his little speech, what to eat, when to eat, how much to eat, when to speak, how much to speak, when to sleep, how much to sleep, etc. Now think about the relatively small number of decisions a person might make that might create the impression that they are “mentally ill.” It is a very tiny

percentage of actual decisions that a person makes that generate behaviors that vary from socially acceptable norms. For the most part, people already have good decision-making skills and just need to be taught how to use them in those instances where they might be making decisions others would consider “unusual.”

The medical profession contributes to the problem through its use of words that bombard people with a sense of hopelessness. “Mental illness” is spoken of as though it were a life sentence. The media perpetuate stereotypical myths every time they report that, “A Former Mental Patient Killed...” The media seldom emphasizes acts of violence that are committed by formerly ‘normal’ people or people with some other disability or physical ailment. Also, when the media speak of “mental illness” they speak of it as though it were a single all-encompassing problem.

The fact that we speak of mental “illness” rather than mental “health” contributes to the overall sense of helplessness and hopelessness of individuals who are psychiatrically labeled. People have said that the loss of the mind is seen as the worst thing that could happen to them as a disability. Additionally, the use of negative descriptive language adds to the barriers that keep people from being able to be more self-determining.

"Why do we use the language of war rather than the language of love in the human services. For instance we talk about sending staff out into the field to provide front line services to target populations for whom we develop and implement treatment strategies whether they want them or not." From "Spirit Breaking: When the Helping Professions Hurt" by Patricia E. Deegan, Ph.D.

Often people who have been psychiatrically labeled are condescended to, patronized, infantilized and otherwise treated like children. Attitudes and language reinforce each other. Both terminology and attitudes must be changed.

## News Media Sensationalism

Sensational and grossly inaccurate and incomplete media reports conjure up stereotypical portrayals of people who have been psychiatrically labeled as crazed and violent lunatics, dangerous to others as well as themselves. The news media often considers stories in terms of how much sensationalism they may generate. They are at liberty to cover a story in any manner in which they choose. They are free to decide which “facts” of a story are relevant. In the past, the color of a persons skin was considered noteworthy whenever covering a crime. Homelessness and poverty are frequently noted with regard to criminal actions. Almost always mentioned is whether someone has a history of using psychiatric services. More recently, it’s usually mentioned whether the person is or was taking any psychiatric medication and often, this fact is blamed as a precipitating factor (both that a person is taking psychiatric drugs and that they are not taking psychiatric drugs).

People should not be grouped as diagnostic categories. Yet, the media commonly speaks of “schizophrenics” or “alcoholics” or other labels instead of referring to people as people. The media often makes “blanket” statements such as, “schizophrenics are dangerous” and they will write and publish editorials that extrapolate from the isolated sensational “Kendra” to push for more forced “treatment” for all people who have been psychiatrically labeled.

It is difficult to overcome the negative image that is portrayed daily in blaring headlines. In July 2003, The National Review carried an article by purported experts criticizing the report of the President’s New Freedom Commission on Mental Health. This article claimed that the report didn’t go far enough in advocating for more use of force in “treating” those who have been labeled as “mentally ill.” The National Review then heaped more criticism upon the report

and advocated for more use of force in the form of an editorial by the editor of the magazine.

The media speculates regarding all forms of what they consider deviance that the cause might be "mental illness." For instance, it is common for the news media to identify "mental illness" as the cause of increased homelessness. The media has the power to scare people into reacting negatively toward people who have been labeled as "mentally ill" because ordinary people use the media as their primary source of information.

### **Fear Factor Fuels Stigma**

A survey, of some 2,000 adults, started annually in 1993 and became three-yearly in 1997. The 2003 findings show a marked worsening of attitudes since 2000 and a general increase in fear and intolerance over the entire 10-year period.

Twenty-five per cent of those surveyed said that people with a history of mental health problems should be excluded from public office, while 16% thought they should not be given any responsibility. Fewer than half disagreed with a contention that women who had been psychiatric in-patients could not be trusted as babysitters.

David Brindle, Tuesday July 01 2003, <http://www.societyguardian.co.uk>

The news media can even generate stigma by omission. A recent article in the September 4, 2003 Los Angeles Times newspaper ("Nurse Injured in Inmate Attack at State Hospital") stated, "Hospital officials said [the nurse] and another employee were talking with resident [the patient] when he suddenly became enraged and started punching the employees." My immediate reaction was to wonder what the staff people might have said to trigger and upset the resident to make him so angry. Of course, it is terrible that the nurse was hurt but, by omitting the patients' side of the story the impression is created that people who have been psychiatrically labeled are all ready to pounce upon and attack innocent bystanders without provocation and without warning.



There are rare instances where the media investigates and creates some pressure to help change things for the better. Clifford Levy won a Pulitzer Prize for his reporting on New York's adult homes and the gross mistreatment of people labeled "mentally ill." The Hartford Courant won national recognition and acclaim for their expose on the use of seclusion and restraints. However, even when the news media get something 'right' there remains an absence of public outcry.

### Entertainment media portrayals

The news media aren't the only ones to sensationalize. The entertainment media also tends to stereotypically portray those with psychiatric labels in either the classic heroic (seldom) or tragic (frequent) sense. Dramatized films have long depicted mental institutions as places of hopelessness, despair, isolation, abuse, and punishment. (In some films the ultimate punishment is to lose one's mind and end up in a mental hospital.) Even though mental institutions are hardly considered places of great healing, the negative portrayal impacts on society by creating an image of those who occupy such places as only worthy of loathing.

People who have been psychiatrically labeled are usually portrayed on television or in the movies as poor, suffering unfortunates who owe all of their recovery (if that's even portrayed) to the expertise and benevolence of some wise and insightful psychiatric professional. Like most stereotypes, these images are full of inaccuracies.

## **MEDIA IMAGES OF MENTAL ILLNESS FACT SHEET**

From <http://mason.gmu.edu/~owahl/MEDIA.HTM>

Americans report that their most common source of information about mental illness is the mass media.

About 6-10% of theatrical films involve portrayals of mental illness, making psychiatric disorder the most commonly depicted disability in that medium.

Approximately 3-9% of the major characters on prime time television are depicted as mentally ill

Mentally ill characters on television are more likely to be depicted as criminals and villains than as honest, productive citizens. They are the only subgroup portrayed more often as villains than as heroes.

Over 70% of mentally ill characters in prime time television drama are portrayed as violent; more than one fifth are shown as killers.

The typical newspaper depiction of individuals with mental illnesses shows them to be psychotic, unemployed, transient, and dangerous.

Research has shown that media depictions of mentally ill killers lead to less favorable attitudes toward community care for persons with mental illnesses.

### Tainted Educational and Professional Training

Higher education and professional training are tainted with out-of-date biased information. Many college textbooks still inaccurately identify “borderline” as on the border between neurosis and psychosis. Textbooks not only lack in using “people first” language, they continue to present antiquated concepts in language that is no longer even used. For example, one textbook classification ranges human intelligence from: idiot, imbecile, moron, borderline, dull, normal, superior, very superior, to gifted. While these words may have had some more precise meaning in the past, they have fallen into disuse. Adjectives like wise, brilliant and genius are used but they have no precision to them. This lack of precision then contributes to a lack of precision later in the career of the professional who

will use such labels as if they had some useful meaning instead of just being stigmatizing and discriminating.

Psychiatrists are generally taught that psychiatric disorders are incurable and will demonstrate a lifelong deteriorating course. There is little taught about recovery and there is little in the training and teaching that is presented by those who are most intimately familiar with the issues – those who have been psychiatrically labeled themselves. Although there is an overwhelming amount of evidence, many mental health professionals and others still believe that recovery is not possible for people who have been labeled with psychiatric disorders. This archaic belief, instilled in the educational process, later contributes to an overall sense of hopelessness that is passed onto the consumers and that creates barriers to individual self-determination.

### Confusion of Mental Health and Criminal Justice Matters

Legislators are often influenced by sensationalism. People outraged by an isolated incident will storm the halls of the legislatures and demand action. However, the actions are seldom well considered and they add to the confusion about the difference between “treatment” and “prevention” and criminal justice matters.

Laws such as Kendra’s Law, Laura’s Law and Brian’s Law get created and are applied in broad brush fashion to large segments of those who are psychiatrically labeled when in fact the situation with Kendra, Laura and Brian were isolated, very individualized events. This results in the laws being unevenly applied. We create laws, after the fact, for a few individuals and specific instances but then those laws get applied unequally to everyone else.

Part of reason that this unequal application of the laws is allowed to happen is that the public (including legislators) links dangerousness with “mental illness.” Dangerousness is very much overestimated by the public, and “mental illness” is NOT the number one determining factor for violence. Violence depends on a number of factors including poverty, age and gender. More than schizophrenia, the greater link is between violence and substance abuse.

### **VIOLENCE AND MENTAL ILLNESS FACT SHEET**

From <http://mason.gmu.edu/~owahl/VIOLFCT.HTM>

**\* THE VAST MAJORITY OF PEOPLE WITH MENTAL ILLNESSES, INCLUDING SEVERE MENTAL ILLNESS SUCH AS SCHIZOPHRENIA, ARE NOT VIOLENT.**

\* The best predictors of violence are youth, male gender, substance abuse, and history of prior violence--not mental illness.

\* The majority (72%) of the mentally ill characters on TV are portrayed as violent.

\* A steady stream of popular movies depicting people with mental illnesses as violent and villainous encourage the public to fear and shun those with mental disorders.

### Negative Stereotyping by Advocates and Others

In the civil rights movement, a person of color was/is the primary spokesperson. In the women’s rights movement, a female was/is the primary spokesperson. In the Disability rights movement, a person with a disability was/is the primary spokesperson. It is generally expected that for any identified group of people to be self-determining, that they speak on their own behalf instead of through intermediaries who are not part of that identified group. However, in the mental health consumer rights movement, there are national organizations of family members, mental health providers and other advocates who claim to be the “voice of mental illness.” The primary spokespeople for those who have been

psychiatrically labeled should be those who have experienced being psychiatrically labeled. They have the best first-hand information on what it's like to live with being psychiatrically labeled.

Sometimes people who do not have first-hand experience of what it's like to be a "mental patient" will speak out as though they have a right to be the authority. Advocates may claim to have spent more time on locked psychiatric units (helping the patients) than the patients themselves. Mental health professionals may claim to have more or better education than most of their patients. Parents may claim to know their child better than the offspring knows him or herself. Friends may claim that a person isn't in their right mind. However, it is the body and mind of the person with the psychiatric label who is directly impacted by stigma, discrimination, mentalism and saneism. It is the person who has been psychiatrically labeled and was/is on the receiving end of "treatment" such as seclusion, restraints, forced drugging, deleterious "side-effects" and the trauma of force. It is the person who has been psychiatrically labeled and was/is sometimes able to experience "recovery." It must therefore be the person who has been psychiatrically labeled who must become the actual "voice of mental illness."

Sometimes well-meaning national advocacy organizations have indulged in "worst-case-scenario fear mongering." They will cite an example of a "worst-case-scenario" as the reason for changing laws to be more oppressive and rob innocent people who have been psychiatrically labeled of their rights. The "worst-case-scenarios" might range from Kendra, Laura and Brian to a parent speaking about their own adult child potentially ending up homeless or worse. These appeals to pity (argumentum ad misericordiam) scenarios are intended to play on the emotions of the public and to influence legislatures. However, this sort of appeal also resembles the worst sort of stereotyping that is done by the media in their negative portrayals.

“... some families have learned to 'turn over the furniture' before calling the police. Many police require individuals with neurobiological disorders to be imminently dangerous before treating the person against their will. If the police see furniture disturbed they will usually conclude that the person is imminently dangerous.”

From, “How To Prepare for an Emergency” by D.J. Jaffe, Nationally prominent mental health activist. <http://www.schizophrenia.com/ami/coping/911.html>

Some people who have been psychiatrically labeled have ended up stuck in the mental health system. Some have been clients of day treatment programs for 10, 15 or even 20 years or more. First level barriers to self-determination are those that come from within the individual as stigma gets assimilated into a person. The next level of barriers to self-determination comes from the service system that allows the continuation of ineffective services for so many years. A third layer of barriers to self-determination can come from family and friends who may encourage loved ones into “treatment” even when that treatment has failed for years and years. A fourth level of barrier to self-determination comes from the greater society where, when they speak of the mental health “community” they speak of only family, friends, administrators, service providers, advocates and others except those who actually have the experience of being psychiatrically labeled.

“People have poorer outcomes if their spouses or family members are highly critical or overprotective.”  
British Psychological Association,  
<http://www.bps.org.uk/sub-syst/dcp/publicat1.cfm>

### Greater Political Concern About Budgets than People

During tight budget times, legislatures have come to talk about “acceptable losses” instead of realizing that people’s lives are at stake. The legislatures also seem to be supporting more institutional based care rather than community based help for people. The first budget cuts that happen are with community

based services while at the same time prison and state hospital budgets either remain the same or are even increased. Cuts of this nature are rather short-sited. Many studies have proven the effectiveness of community-based services in terms of both their ability to help people improve their lives and in terms of their cost effectiveness over the long-term. Budget cuts seem to be prioritized according to their potential political impact. Therefore, cuts to a disenfranchised population are more likely than cuts to services that would repair a pothole in the road of a nice middle-class neighborhood.

There is a scarcity of access to and reimbursement for a wide range of community-based services and supports, such as employment and housing, is also inadequate for people labeled with psychiatric disabilities and serves to prevent their successful recovery. Access and choice are critical for individuals with diverse needs. Further, communities are in the same quandary as the community mental health system – they are unsure of their purpose and mission. Is it to produce more billable hours of service or to provide actual services to people in ways that help them to become more self-determining?

### Misunderstandings of Ordinary People (NIMBYism)

Discrimination against people who have been psychiatrically labeled has even resulted in new special words to describe the phenomena – NIMBYism (Not In My Back Yard) for example. Everyday people on the street are the source of the NIMBY (Not In My Back Yard) phenomena and they are driven by the sources of misunderstanding that tap into their feelings of fear and loathing. The common person knows little about “mental illness” and often equates it with mental retardation. These misconceptions usually come from the media.

Less able to be explained are the misconceptions of the general practitioner of medicine or law enforcement officers. Despite their greater contact and

sometimes better education, they seem filled with misconceptions generated by the media.

People who have been labeled with mental illness have described stigma as a second level of suffering, and say it is almost worse than having the “mental illness” itself. Stigma is different than being actively discriminated against; it is the social inequities that result from the collective neglect of society.

### **MENTAL ILLNESS STIGMA FACT SHEET**

From <http://mason.gmu.edu/~owahl/STIGFACT.HTM>

Americans have little doubt that mental illness stigma exists. In different surveys, two out of three representative Americans, 88% of people with severely mentally ill relatives, and 91% of respondents who had experienced mental illness, reported that they believed there is strong stigma attached to mental illness.

The public tends to attribute unfavorable characteristics to those with psychiatric diagnoses or treatment. People with mental illnesses are viewed as inferior, flawed, dirty, dangerous, unpredictable, and unmotivated.

The public tends to avoid and reject those with histories of psychiatric treatment. They express reluctance to employ, work with, socialize with, or rent to people who have had psychiatric treatment or psychiatric diagnoses.

People with psychiatric disorders often encounter discrimination in employment, housing, and educational opportunities. Stigma is also thought to contribute to inadequate insurance health coverage for mental health problems and to low levels of public funding for mental illness treatment and research.

People with mental illnesses may be reluctant to seek help because of stigma and frequently conceal information about their illnesses and treatment because they fear negative reactions from others.

Stigma, and the feared reactions of others, undermines treatment and recovery. Self-esteem is damaged. Fear and rejection are encountered when understanding and support are particularly needed. Involvement in community life and productive employment are more difficult.

Mass media depictions of mental illness help to perpetuate stigma with their characteristically inaccurate and unfavorable stereotypes of people with psychiatric disorders.



I visited a drop-in center in a small town in Oregon. One member reported that whenever she visited the local McDonald's restaurant, she was always given lousy food (cold or ill prepared). Other members confirmed this and everyone claimed that the only reason for this behavior was that the member was known to that establishment as "mentally ill."

### Toxic Environments (Neighborhoods)

Many mental health consumer/survivors are faced with poverty issues that lead them to live in ghetto neighborhoods with high crime and violence. Drive-by shootings, drug dealing and other such activity create toxic neighborhoods where it is hard to imagine how anyone could grow to be emotionally healthy. Perhaps studies should be done to see if it's even possible to "recover" in such environments.

Although mental health underwent an era of deinstitutionalization, there seems to be an opposite trend today. There are programs where mental health professionals hand deliver medications direct to the persons door twice a day. There are depot (long-acting) injections of medications that, while supposedly freeing a person from having to be bothered with daily medications, are in effect, creating hospitals without walls. People in these programs sometimes feel as though they've almost never left the hospital. The threat of force for non-compliance seems as real and coercive as though the person were still within an institution. Their lives can become nearly as regimented as in a hospital and they can have contact with professional staff almost as often. The result has been a blurring of the line between institutional care and community integration. If communities are supposed to be healthier places to grow and recover than institutions, then it is surely a barrier to growth and recovery when we turn our communities into institutions.

## Social Indifference

There is a social indifference that permeates society when confronted with something distasteful or unpleasant. People will step over those who are homeless on their way to work. Eventually, the people who are homeless disappear from consciousness and fade completely into the background. Even when confronted with the epidemic of tardive dyskinesia in this country, people will shy away and not want to know about it.

The public's attitude towards abuse of people diagnosed as mentally ill has to involve more than the "out of sight, out of mind" attitude that previously kept many in the past, locked up in basements and attics. One would expect by now that people are aware of what can and does happen in mental hospitals and other facilities. It's possible that there is no longer an abuse a person labeled as mentally ill can experience that would engender popular outrage.

The public tends to avoid and reject those with histories of psychiatric treatment. They express reluctance to employ, work with, socialize with, or rent to people who have had psychiatric treatment or psychiatric diagnoses. The public's opinion of people with mental illness is that they are unpredictable, violent, and dangerous. Perhaps, like the homeless who are stepped over and around every day by people going to work, those who have been psychiatrically labeled have become invisible to the consciousness.

## Western Medical Model Bias

We are raised in this country, in this culture to believe that doctor is right, doctor is always right, trust doctor! If we have a problem we must go to doctor and do exactly as doctor says so that the problem can be resolved. This is the source of the myth of the all knowing (omniscient), all-powerful (omnipotent) god-like

doctor. Doctors are first and foremost, people with all of the limitations of other people. However, our faith in doctors can lead us to trust too much and doctors may sometimes use and abuse that trust. People who have been psychiatrically labeled often speak of how their doctor will urge them to take medication without taking the time to provide the information necessary for a true informed consent.

Western medicine is generally framed in terms of pathology. Extreme emotional and spiritual states going on within a person might not be considered negatively by the person having those experiences but according to western medicine those experiences are judged negatively with both a negative diagnosis and prognosis. An altered state experience may connect to and help build a person's capacity for spiritual understanding or development, or for sensitivity to others, or their capacity to care deeply, etc. Trying to find causes within a western medical model is like trying to find a cause for creativity or high intelligence or ability in sports, etc.

“Adherents to the medical model believe that a disabled person's problems are caused by the fact of his or her disability and thus the question is whether or not the disability can be alleviated. Advocates of the disability-rights model, on the other hand, believe that a person with a disability is limited more by society's prejudices than by the practical difficulties that may be created by the disability. Under this model, the salient issue is how to create conditions that will allow people to realize their potential.”  
(Carol Gill of the Chicago Institute of Disability Research)

The disability movement recognizes eugenics as a real danger to be taken seriously. Discussions of causality for “mental illness” are not just a question of curiosity or differing beliefs but may become justification for eugenics. On the one hand causation is important because of where it might lead. But, on the other hand, such discussions are unimportant because they miss and distract from the point of, “nothing about me without me!”

## Other Issues; Language and Employment

Even within the mental health system, there is language that is stigmatizing and discriminatory. The system uses the word “treatment” and yet that word has been twisted by the system and perverted beyond recognition. You can be locked up against your will, literally and figuratively stripped (of your clothes and of your rights) and forced into bondage and solitary confinement and then injected with powerful and painful drugs and still have it called "treatment." In every other possible realm on earth, this would be considered torture and not "treatment." A fifteen-minute appointment to renew drugs every two weeks or month is also called "treatment."

"To be a mental patient is to participate in stupid groups that call themselves therapy – music isn't music, it's therapy; volleyball isn't a sport, it's therapy; sewing is therapy; washing dishes is therapy. Even the air that we breathe is therapy – called milieu." -Rae Unzicker

Normal behaviors are NOT symptoms. Normal people can have a bad day, an "off" week and even a "down" month. However, if a person who has been psychiatrically labeled exhibits those normal behaviors on the job, they may be asked if they took their medications or if someone needs to call their psychiatrist. Everything, someone who has been psychiatrically labeled does, becomes filtered through a lens that sees them as a mental patient. Other people might have a high-energy day but a person who has been psychiatrically labeled will be called “manic” and, while other people might have a down day the person who has been psychiatrically labeled will be called “depressed.”

Psychiatric drugs have many effects. Some of those effects are desired and others are undesirable. Those effects that are not desired are called “side-effects.” Calling something a "side-effect" obscures, trivializes and minimizes the resultant pain, suffering and misery that can be caused by psychoactive drugs and in doing so, it discounts the experiences and perceptions of the person

taking the medication. It's easy to ignore weight gain, loss of libido and other unpleasant effects if they are just "side-effects" that are happening to someone else.

When the system does try and help us obtain employment it's usually in the form of helping us secure a job. It's seldom in the form of helping us plan and fulfill our individual dreams on a career path. We are usually pushed into jobs that are low level, dead end employment. These low-level jobs even have a nickname coined for the mental health industry – the five 'F's – food, filth, flowers, filing and fashion. Food refers to fast food or bakery sorts of jobs; filth refers to janitorial type jobs; flowers refers to gardening or landscaping type jobs; filing is low-level secretarial type jobs; and, fashion is work in thrift stores or similar menial type jobs. It's hard to get a job when many employment applications and drivers' license applications ask about past psychiatric history and it appears that the rationale for asking is to deny jobs or the license. However, loss of job can result from lying on the application form. The system rarely gives any help for this Catch-22 dilemma.

There are many other concerns beyond the scope of this paper. One concern would be to address how people who have been psychiatrically labeled are treated in the emergency room departments of general hospitals. Another whole paper would be necessary to address the legal inequities contained in the concepts of mixing the judicial process with the "treatment" process via commitment and mental health courts.

### Conclusion

People who have been psychiatrically labeled have the same problems as any other disenfranchised group. They face poverty issues as well as stigma and discrimination in other areas of life. They face similar issues to those faced by

others with disabilities but they also have some issues that are unique to being psychiatrically labeled. As far as anti-stigma interventions go, one-size doesn't fit all because there are so many different opinions and ideas out there about people with mental illness. And there is no such thing as the 'general population' or 'society' as a whole, there are just different groups of people with different opinions.

People labeled with psychiatric problems need to be educated and taught how to fully exercise their franchise as citizens. They need to be encouraged to vote and to make their issues known to legislatures. They need to lobby and even potentially demonstrate against media that creates negative stereotypes. Many other solutions become apparent as people become more aware of the various issues of stigma and discrimination that face them and others. Discussions must take place to explore these issues but people who have been psychiatrically labeled must be the first and primary voice at the table. "Nothing about me without me."

# The *Contract with Women of the USA* A Model of Policy Advocacy to Promote Self-Determination

**By Leslie R. Wolfe, Ph.D., President, Center for Women Policy Studies**

## **Preface – Creating the *Contract with Women of the USA***

The 1995 United Nations Fourth World Conference on Women in Beijing adopted a *Declaration and Platform for Action*, unanimously endorsed by 189 government delegations, including the United States. These governments thus created a powerful agenda for women’s equality and human rights worldwide – and an important organizing and advocacy tool for social change. Indeed, feminist organizations, scholars, and policy makers in many countries have used their governments’ endorsement of the *Platform* at Beijing to press their leaders to make its promises a centerpiece of public policy and social programs.

The *Platform for Action* addresses 12 “critical areas of concern” that define obstacles to the full equality of women and girls: poverty, education and training, health, violence, armed conflict, the economy, decision making, institutional mechanisms for the advancement of women, human rights, media, the environment, and the girl-child. The accompanying *Declaration* “reaffirmed the commitment of Governments to eliminate discrimination against women and to remove all obstacles to equality. . . . [and] recognized the need to

ensure a gender perspective in their policies and programmes” (United Nations Department of Public Information, 1995).

As Bella Abzug declared in Beijing: “We have a contract here – that’s what we call the *Platform for Action* from the Beijing conference – a contract with the world’s women. It may not be legally binding, but I believe it is politically binding” (Center for Women Policy Studies, 2000a). Together, the Center and Bella Abzug’s organization, the Women’s Environment and Development Organization (WEDO), took steps to make this vision a reality in the United States.

Our partnership and the **Contract with Women of the USA** began almost by accident – but really because we were in the right place at the right time with similar purposes – and we were able to immediately understand, based on our years of policy advocacy, that we had experienced a powerful “explosive moment” that would move our women’s human rights agenda forward (see Wolfe and Tucker, 1995, for an explanation of the theory of “explosive moments”). At the Center for American Women and Politics (CAWP) Fourth National Forum for Women State Legislators in San Diego in November 1995, Bella Abzug gave a keynote address about the Beijing conference and the Platform for Action.

Later that same day, Center president Leslie R. Wolfe and vice president Jennifer Tucker convened a long-planned informal meeting with several women legislators to discuss strategies to respond to anti-woman policies generated by the right wing in their states and to promote a multiethnic



feminist policy agenda. This conversation – and the inspiration Bella’s speech gave to legislators -- provided the initial impetus for the Center to find a new approach to implementation of the Beijing *Platform for Action*.

Together, the Center and WEDO “translated” the Beijing *Platform for Action* into a set of 12 principles that are specifically relevant to promotion of women’s human rights in the United States. We named it the ***Contract with Women of the USA*** to reflect Bella’s assertion that this is a “politically binding” contract – a tool for policy advocacy that enables us to hold our Nation’s leaders accountable for implementing the commitment they signed in Beijing.

In fact, the ***Contract with Women of the USA*** reflects many of the enduring principles that have guided the Center’s work since its founding in 1972 – ending the burden of poverty, ensuring access to quality health care, guaranteeing women’s sexual and reproductive rights, ensuring women’s workplace rights, promoting educational equity for girls and women, and ending violence against women, for example.

Further, the ***Contract*** -- and the **State Legislators Initiative** through which we implement it -- represents a policy tool that brings the Center’s unique multiethnic and multi-issue feminist mission into the mainstream. Indeed, the Center’s mission and theory in many ways operationalize the academic term “intersectionality.” We use a variety of strategies to put our multiethnic and multicultural feminist ideology into practice – thus implementing “intersectionality” in the public policy realm.

The Center grounds its work in the belief that policy must address the *combined* impact of women's multiple identities – by gender, race/ethnicity, socioeconomic status, sexual orientation, age, disability status, and immigration status. The Center's work seeks to reflect women's kaleidoscopic diversity and to bring the self-defined needs of women, particularly women of color, to the policy table.

A hallmark of the Center's 31 year history as an institution with a multi-issue focus has been our ability to identify cutting edge issues and trends that are not yet the topic of public policy debate, to define them from women's diverse perspectives using research and policy analysis methods, to shape multiethnic feminist responses and research-based policy options, and to produce materials that can influence the coming debate and help transform the public discourse.

We also apply our multiethnic feminist lens to our assessment of current social, economic, and political trends – especially to women's policy issues that have become “chic” -- to understand their potential impact on women who have been rendered invisible and marginalized by the prevailing assumption that “all” women will by definition benefit equally from certain progressive policy options, such as unpaid family leave, for example.

Because our primary audiences are policy makers and advocates, we often use clarifying images to characterize our stereotype-breaking and norm-changing ideological and theoretical assumptions. For example, many of our colleagues do not immediately understand why we consider “inclusiveness” to

be an inappropriate term and strategy; we explain that the term and the practice – in both activism and research -- imply the need to understand “the other” in the context of what is assumed to be “real” and normative – that which is white, middle class, heterosexual, and non-disabled.

To concretize our mission to create and define a new norm in “user-friendly” terms, therefore, we often use the image of women worldwide as being “in the same boat.” Some of us -- by virtue of our race, ethnicity, class, marital status, disability, sexual orientation, nation of origin – are in first class cabins, some are working in the kitchen, and some remain locked in the cargo hold. The boat is stratified by race, class and gender; it is often brutal and dangerous – and it is governed by patriarchal assumptions. Our goal is to develop research-based policy analyses that will change the norms, assumptions, and practices of the institutions that govern our lives.

The Center conducts its policy research and advocacy in three ways. First, we conduct original policy-relevant research and policy analyses on underexplored issues and with marginalized groups of women; the Center’s research is designed to bring the self-defined needs of women of color from margins to center, to break stereotypes about women and girls, and to look at issues in true multiethnic perspective that includes both women of color and white women. Second, we “translate” existing data and research studies into policy-relevant terms and formats that policy makers will find accessible and significant for their own work. And third, we convene diverse groups to take

the conversation on difficult and/or new issues to the next level (see Wolfe, 2001).

Given its unique mission and strategies, the Center was especially well positioned to take on its special role in post-Beijing implementation activities in the United States defined by our ***Contract with Women of the USA State Legislators Initiative***.

Indeed, the Center's "niche" since 1996 has been to build a network of women state legislators – and several men – in all 50 states who endorse the ***Contract's*** principles and work to implement them in their states. In this era of devolution of many federal responsibilities to the states, the leadership of women state legislators is especially crucial in the struggle to preserve and expand women's human rights. And a powerful group of legislators worked with the Center to launch the ***Contract with Women of the USA*** in 1996.

### **Launching the *Contract with Women of the USA State Legislators Initiative***

On March 8, 1996 – International Women's Day – the Center and WEDO officially announced the creation of the ***Contract with Women of the USA*** and the Center launched the **State Legislators Initiative** with women's legislative caucuses in six states – Arizona, California, Illinois, Maryland, Minnesota and New York. Women state legislators in these states hosted media events in their state capitols to publicly pledge their support for the ***Contract's*** principles and to announce their own ***Contracts*** with the women of their states. On April 15 – Income Tax Day – women legislators in Florida and

Oregon reflected on the persistence of the wage gap and women's lower economic status in announcing their state **Contracts** at a series of press events.

In each state, legislators used the national **Contract with Women of the USA** as a model for creation of their own state-relevant and specific documents and activities. In Arizona, a coalition of legislators and members of the Arizona delegation to the Beijing conference launched the **Contract with the Women of Arizona**. California legislators announced the **Contract with California's Women**. And Illinois legislators introduced a resolution in their legislature supporting the **Contract with Women of the USA**.

More than 25 Maryland women legislators introduced the **Pledge to Maryland Women** as a legislative resolution. And the Minnesota Democratic Farmer Labor (DFL) Women's Caucus announced the **Covenant with Minnesota Women**. The New York Legislative Women's Caucus announced **Women 2000: Putting Women on the Public Policy Agenda**, a five year plan to integrate women's issues into the state's public policy agenda.

The Center was successful in these states largely because women legislators already were well organized and committed to promoting a women's issues policy agenda – through their existing women's legislative caucuses. However, it soon became clear that replicating these first eight state **Contracts** in other states that had less active legislative women's caucuses, or that had not yet created caucuses, would strain the Center's staff and financial resources and likely produce limited success. We therefore

decided to create a different strategy to engage far larger numbers of legislators throughout the United States in the **State Legislators Initiative**.

### **Building the State Legislators Initiative**

The Center therefore created a **National Honor Roll of State Legislators** and invited all 1500 women state legislators in the United States to sign on to the principles of the ***Contract with Women of the USA*** and, thereby, become members of the **Honor Roll**. On Women's Equality Day, August 26, 1996 – the 76<sup>th</sup> anniversary of women's suffrage – we announced the charter members of the **Honor Roll** (current and alumnae members of the **Honor Roll** are listed at [www.centerwomenpolicy.org](http://www.centerwomenpolicy.org)).

The **Honor Roll** now numbers 500 current and former state legislators – both women and men. It is a powerful network of policy makers who support the women's human rights agenda reflected in the **Contract with Women of the USA**. Though ours is not the only network of women state legislators in the United States, it is the only one which is explicitly women's issues-based and built on a commitment to a pro-choice, multiethnic feminist policy agenda. We therefore have created a unique “niche” for the Center among other national women's organizations and organizations that work with state legislators.

The legislators who participate in our work are the ones most likely to take leadership on legislative and policy initiatives to implement the **Contract's** principles and to stand up for women's rights in their legislatures, in their own districts, and in the federal policy arena. Today, **Honor Roll** alumnae serve in

the United States House of Representatives, in the United States Senate, and in statewide offices – including Governor.

### **Creating New Materials**

The Center – serving as their “national staff” – provides these legislators with special support and assistance. And this is a key to our success, as we perform the duties both of state legislative staff members and national policy leaders. For example, we maintain a state legislative clearinghouse for innovative legislation on women’s issues – and share individual legislators’ model bills with their colleagues in other states.

***State Legislative Report.*** Our newsletter, the *State Legislative Report*, provides updated information on federal policy and legislation and on state efforts to implement the **Contract’s** principles. Starting in 2002, we have published the newsletter online – sending it by email to state legislators and posting it on our website – while still faxing or mailing it to those legislators who do not use email. Beginning with the February 2003 issue, we substantially revised the newsletter’s format -- to make the *State Legislative Report* shorter, to produce it every other month (or six times per year), and to focus each issue on a particular policy concern.

For example, the February 2003 issue addressed some of the reproductive rights and health issues currently being debated nationally and in state legislatures across the country. The April 2003 issue highlighted progress on another of the Center’s signature issues – access to postsecondary education as the route to economic self-sufficiency for low

income women, including recipients of welfare assistance under the Temporary Assistance for Needy Families (TANF) program. And the June/July 2003 issue focused on a relatively new policy issue for state legislators – but one that the Center has been addressing since 1999 – sexual trafficking of women and girls into the United States.

**Action Alerts, Op-Eds, and Letters to the Editor:** Our other materials for legislators respond to their self-expressed need for short pieces that they can use immediately. Thus, we send regular *Action Alerts* on timely federal and state policy issues. For example, we have produced a series of *Action Alerts* to encourage legislators to share information about state welfare reform needs with their national representatives during the TANF reauthorization process. We also have sent legislators several *Alerts* over the years on the range of reproductive rights and health issues – from the impact of the Global Gag Rule on women worldwide to state legislative efforts to overturn *Roe v. Wade*, for example. All of these *Alerts* remain available to legislators for up to five years.

Because legislators' voices must be heard in their own communities on key women's policy issues, we prepare op-eds and letters to the editor for legislators to place in their own local newspapers – thus bringing the Center's research and policy analyses to larger audiences and expanding awareness of a range of women's human rights issues nationwide. For example, we have used this strategy to encourage legislators to educate their constituents on the international women's rights treaty – the Convention on the Elimination of All



Forms of Discrimination Against Women (CEDAW), sexual trafficking of women and girls as a US problem, HIV/AIDS prevention for girls and young women, and the importance of college as a route out of poverty for women.

**Policy Research and Analyses:** In addition, the Center produces a variety of other materials for legislators – all designed to help them decipher and manage the impact of the “devolution revolution” -- new federal laws that simultaneously delegate more responsibility to the states while restricting federal financial support and creating new limits on traditional areas of state jurisdiction. We produce extensive policy analyses for both federal and state policy makers – and for the advocates who are policy influencers at both levels.

Our 2002 report, *From Poverty to Self-Sufficiency: The Role of Postsecondary Education in Welfare Reform* (available for download at [www.centerwomenpolicy.org](http://www.centerwomenpolicy.org)), is the first to include both a persuasive, research and data-based argument for allowing TANF recipients to count postsecondary education as an allowable work activity and also an extensive policy analysis of state laws implementing the TANF program since its passage by Congress in 1996. Indeed, we found that 49 states and the District of Columbia currently include some form of postsecondary education as an allowable work activity for TANF recipients – information that policy makers and advocates have found invaluable during the Congressional reauthorization effort for TANF during 2002 and 2003.

We also share the Center's other publications with legislators, thus providing them with more in-depth research and policy analyses on such key issues as the women's HIV/AIDS epidemic in the United States (see Gaberman and Wolfe, 1999; Wolfe et al, 1999; Rochelle and Wolfe, 1999), Medicaid managed care (see Center for Women Policy Studies, 1998a), violence against women and girls (see Fiduccia and Wolfe, 1999; Copeland and Wolfe, 1991; Center for Women Policy Studies, 2001), and work/family and workplace diversity (see Tucker et al, 1999), for example. Based on legislators' responses, we develop action alerts, action kits, op-eds, and letters to the editor on these and other issues. Indeed, our first two *State Legislators Action Kits* – on access to postsecondary education for low income women and on women and HIV/AIDS – “translate” much of our research and policy analysis into short pieces, or fact sheets, that focus on the policy implications for the states.

### **Convenings**

From the Center's early days, we have considered our convening function to be a significant part of our policy research and advocacy programs. Indeed, we regularly conduct policy and research seminars and think tanks that bring together scholars, activists, practitioners, and policy makers to discuss difficult, controversial, and/or new trends and topics – with the goal of shaping woman-focused research, policy and advocacy agendas. For example, we brought our research on women's health decision making to a group of practitioners, state legislators, corporate executives, and researchers

at our 1996 **Symposium on Building Partnerships for Women's Health** in Washington (Center for Women Policy Studies, 1997).

Our 1997 **Summit on Girls and Violence** brought together a key group of advocates, researchers, educators, funders, and policy makers to strategize about ways to galvanize attention to the findings of the Center's research, and the research and practice of **Summit** participants, to focus national attention on the devastating violence that plagues the lives of girls and young women – and on the increased willingness of girls to become violent in response (Center for Women Policy Studies, 1998b).

Finally, since its creation in 1987, the Center's **National Resource Center on Women and AIDS Policy** has convened several seminars and think tanks that break new ground in our understanding of the women's HIV/AIDS epidemic and the link between HIV, substance abuse, and reproductive rights issues. For example, our 2000 **Policy Seminar on HIV and Drug Policies** was the first to bring together women involved in substance abuse policy reform and women working on HIV/AIDS to discuss the extent to which policy development in both fields is designed to restrict women's reproductive rights and health (Center for Women Policy Studies, 2000b). And, with the AARP Women's Initiative, the Center convened the first-ever **Seminar on Midlife and Older Women and HIV/AIDS** in 1993 – at which policy makers and advocates learned from leading researchers and practitioners about the then virtually invisible HIV epidemic growing among older women (Center for Women Policy Studies, 1994).

When we launched the ***Contract with Women of the USA State Legislators Initiative*** in 1996, we expanded on this traditional convening strategy to develop specific, focused efforts to bring women legislators together. Our decision making about format, location, and approach was based in large part on our conversations with legislators about what they most want and need from meetings – namely, the opportunity to spend time together to learn about substantive issues that affect them and the women they represent and to learn from each other about what works to make change. In response, we convene workshops and other sessions – including luncheons with nationally known speakers – at the annual conferences of the National Conference of State Legislatures (NCSL). We conduct legislative briefings and legislative exchange sessions at NCSL, in Congress, and within specific states.

**National Conference of State Legislatures:** Because the NCSL annual meeting traditionally has been the prime opportunity for legislators to gather together, we have focused substantial resources on this event. Because we are not officially part of NCSL – which is a well-staffed membership organization of the 50 state legislatures – we function as an “ancillary group” and hold our sessions during the specific times allowed by NCSL. While this limits our options, we have found NCSL staff and elected leaders to be supportive and helpful and we have convened several sessions as part of NCSL annual meetings in recent years.

Our 2000 policy seminar at NCSL, entitled **Women State Legislators on the Cutting Edge – Women’s Health Policy Seminar**, brought together 23 women state legislators to consider issues of access to health care for low income women. Nearly 50 legislators attended our 1999 **Roundtable on Sexual Trafficking of Women and Girls** at NCSL – an exceptional turnout for an issue that had not yet reached national prominence; at this roundtable, many state legislators learned for the first time about proposed federal law (since passed) and about the role of states in addressing this global/local crisis. Demonstrating the extent to which our work since 1999 has had an impact, we were invited to make the overview presentation on trafficking as a state policy issue at an official 2003 NCSL-sponsored session on human trafficking – another first.

NCSL also sponsored a major session on **Women and HIV/AIDS** in 1998 – to showcase then-Miss America Kate Shindle’s work on HIV prevention. The Center for Women Policy Studies, in partnership with the NCSL Women’s Legislative Network, put the session together and brought a group of experts on women and AIDS to the attention of participants – the first time, again, that these critical women’s issues were addressed by NCSL and, sadly, the last to date.

In recent years, again based on our conversations with legislators, we have expanded our convening strategy to initiate a series of “legislative exchange” sessions that respond to legislators’ desire to strategize together on difficult issues. For example, we have convened two legislative exchange

sessions on **Threats to Women's Reproductive Rights and Health** at NCSL – the first in 2001 and the second in 2003. And we also have convened two legislative exchanges at NCSL on access to postsecondary education for low income women – in partnership with the National Education Association (NEA). The first exchange, in 2002, focused on **Preparing for TANF Implementation**, and the second, in 2003, expanded the focus to include the upcoming reauthorization of the *Higher Education Act* by Congress in 2004.

Our **Legislators Luncheons** at NCSL have proved to be one of our most effective strategies – partly because we present excellent speakers and partly because we provide a comfortable atmosphere that promotes their own networking – and delicious food, the importance of which never should be underestimated! Our 2001 luncheon energized legislators on the needs of low income women facing domestic violence and our 2003 luncheon brought them an analysis of the impact of the Supreme Court's affirmative action rulings on their states.

These events go a long way towards engaging state legislators with the Center in both personal and political ways. As they listen to us and our excellent speakers, as they share food and conversation with our staff and each other, they become even more involved with the Center as an entity they care about – as well as an organization they can rely upon for experts assistance in their own legislative work.

We also invite our sister organizations that work with women state legislators to join us as co-sponsors of the **Legislators Luncheons**. This

further deepens our relationships with such organizations as the NCSL Women's Legislative Network, the Center for American Women and Politics (CAWP), the Women Legislators Lobby of Women's Action for New Directions (WILL/WAND), and the National Organization of Black Elected Legislative Women (NOBEL/Women).

**Congressional and State Legislative Briefings and Exchanges:**

State legislators rarely have the opportunity to testify before Congress on women's rights issues or to spend time in meetings with Members of Congress, on Capitol Hill – with the exception, of course, of their own Representatives. The Center's Congressional Briefings have begun to change this and, again, to deepen legislators' engagement with the Center. In fact, legislators who speak at these Briefings become committed to the Center in a new way, as we provide them with national visibility and with new opportunities to share information and strategies with their national counterparts.

To follow up on our Congressional Briefings, we bring the same issues and messages home through state briefings and legislative exchange sessions. In 2002, for example, we conducted three Congressional Briefings – followed by state sessions in 2003.

**Reproductive Rights:** We sponsored a groundbreaking **Legislative Exchange on Reproductive Rights and Health** in June 2002 for the *Congressional Pro-Choice Caucus* of the US House of Representatives. This Briefing brought four women state legislators from four states to Capitol Hill to share their experiences with leaders of the *Congressional Pro-Choice Caucus*

and Congressional staff. Although they are fighting on very different battlefields, pro-choice state legislators and Members of Congress face parallel reproductive rights and health challenges. This Briefing gave them an opportunity to come together to share strategies and struggles, learn from each other, and build shared networks of support.

Following the success of the Congressional Briefing, we convened two state legislative exchange sessions in 2003 – both of which produced unexpected results that demonstrated the importance of such convenings. We began with a legislative exchange in Colorado, a state whose legislature is not led by a pro-choice majority and whose pro-choice legislators rarely succeed in passing bills they introduce. And yet, 10 state legislators participated in the session, and inspired us with their commitment to promoting women’s reproductive rights in their legislature – despite their minority status. These 10 legislators agreed to create a new “Reproductive Freedom Caucus” and to invite all 100 members of the Colorado legislature to join. This was a stunning outcome and will, we hope, help energize pro-choice forces in the legislature and throughout the state.

We convened our first regional legislative exchange -- for pro-choice legislators from two states, Maryland and Virginia. The session gave them an opportunity – which they had never had before – to examine lessons learned in their recent legislative sessions and to develop strategies for the 2004 session. We used this regional strategy for the first time because these neighboring states are in contrasting policy making postures with regard to



women's reproductive rights. For the first time in several years, Maryland's governor is not pro-choice, though the legislature's majority remains pro-choice. In Virginia, the governor now is pro-choice but the legislative majority is strongly anti-choice. Given these mirror images, we thought it would be useful for these legislators to come together for a freewheeling discussion. Despite their differing policy environments today, legislators from both states acknowledged how swiftly things can change and agreed to consider creating their own state reproductive rights legislative caucuses.

**Welfare Reform:** Four Members of Congress hosted our 2002 **Congressional Briefing on Postsecondary Education as an Effective Welfare Reform Strategy** and our speakers included three women state legislators who had introduced bills to allow TANF recipients to remain in college, as well as two college professors who work with low income students -- and thus were able to bring to Capitol Hill the perspectives of both colleges and their low income students.

This Briefing also marked the beginning of our long term partnership with the National Education Association to address these issues at both the federal and state levels – a partnership that has been invaluable to the Center as it has opened access to educators nationwide who are supportive of legislators' efforts to maintain educational opportunities for TANF recipients and other low income women.

We convened our first state briefing in St. Paul, Minnesota in November of 2002 – shortly after the mid-term election which altered the

state's political landscape. While we had carefully crafted the agenda for the session, which we titled **From Poverty to Self Sufficiency: Preserving Postsecondary Education for Low Income Women**, legislators needed to process the election results and share their concerns about the election's potentially negative impact on their efforts to maintain a focus on higher education for low income women. Indeed, they were most interested in our analysis of changes in the national political landscape since the elections and on the expected restrictions coming with reauthorization of TANF.

Legislators also focused on several issues we had addressed only peripherally – such as the impact on recipients of caseworkers who discourage them from education and strategies legislators can use to influence colleges and universities in the districts they represent, to ensure access for TANF students. Again, we learned from legislators and advocates what their needs are and this has helped us plan our upcoming Congressional Briefings – in anticipation of reauthorization of the Higher Education Act – and state legislative exchange sessions.

**Girls and Young Women with Disabilities:** The Congressional Bipartisan Disabilities Caucus and the Congressional Caucus for Women's Issues co-sponsored our Congressional Briefing on girls and young women with disabilities. In fact, this was, to my knowledge, the first time there had been such a briefing focused on disabled girls in the halls of Congress. In contrast to our other Congressional Briefings, we invited disabled women experts to present these issues to the Members of Congress who lead the

Disabilities Caucus, to Congressional staff, and to disability advocates who joined the audience.

Disability policy and programs rarely consider the particular needs of girls and young women. In short, the field rarely applies the gender lens to its analyses. Therefore, our goal was to provide new information to policy makers and advocates alike rather than to bring legislators to Congress to share their experiences. We now hope to work with disabled women experts in other states to bring their perspectives to state legislators who have not yet become involved in disability policy development that will benefit girls and young women.

To begin this state strategy, the Center partnered with the California-based Disabled Women's Alliance to convene our first state **Legislative Briefing on Girls and Young Women with Disabilities** in Sacramento for California state legislators, staff members, and advocates in August of 2003. We entitled the Briefing "Strong Proud Sisters," after the title of a Center report (Rousso, 2001). We now have developed a model for such state Briefings that will enable the Center to engage legislators on these issues in partnership with a local or statewide disabled women's organization – and then leave the educated policy makers and advocates behind to carry on independently. In many ways, therefore, the Center is engaging in education of legislators and capacity building of state organizations that now are poised for substantial success as policy advocates.

## Translating the Model – Other Movements, Other Issues: Discussion Questions

The following discussion questions are just a beginning. I hope they will help participants shape their own strategies for building a policy advocacy effort for the self determination movement. And I hope that learning about the Center’s model will be beneficial and that participants in this conference will look back years hence to think of this session as a launching pad.

But first, you need to consider such questions as:

What is the comparable “hook” to the ***Contract with Women of the USA*** for the self-determination movement?

What are the signature policy initiatives the movement seeks to implement in the states?

Which states are most likely to respond initially – i.e. to function as policy laboratories for the new policy advocacy component of the movement? Criteria for selecting these states might include: presence of relatively strong state and/or local organizations that could take the lead; presence of expert advisors, researchers, advocates; presence of policy makers who are supportive.

Who are the key movement allies on shared policy concerns – including, for instance, women’s groups, parent groups, educators, disability rights groups, independent living centers?

Who are the key movement adversaries and how can they be dealt with?

What are the top five key policy issues that you should begin with – to create a “Contract” or “Bill of Rights” or other document that clearly defines the movement’s policy mission?

What strategies – conferences, materials development, research, legislative exchanges, etc – are most likely to be effective on these issues?

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# Mad Movements: Chaordic Paths in Mental Health Activism Toward a Revolution of Empowerment

***By David W. Oaks, Executive Director, MindFreedom Support Coalition International***

*Chaordic*: existing in the phase between order and chaos.

"I propose that we of the disability communities unite with all who love justice to lead a revolution of empowerment." — Justin Dart, Jr.

**Summary:** An underlying principle of self-determination is peer mutual support. This same principle of mutual support applies to successful community organizing of social change actions and movements to better the lives of psychiatric survivors and mental health consumers. Victories are usually not won in a vacuum; there is often a synergy, a complex cyclical relationship between individuals, groups, allies and other movements. The creative tension may seem contradictory at times, but many victories have been won on this edge between chaos and order. This chaordic edge may seem familiar. This edge is the tumultuous process of democracy itself. This edge is where the power of democracy meets the mental health system, and creates a revolution.



## **I. Introduction: Mutual Support With Other Social Change Movements**

It's fitting that we're talking about community organizing to better the lives of people who have been given psychiatric diagnoses, right here in the Chicagoland area with its rich historic traditions of social change led by labor leaders, poor people, African Americans, women, and even hobo kings.

Here in Chicago we find the legacy of Hull House founded by Jane Addams, who in 1882 had a turning-point experience with "hysteria" which would now be called depression. She is now credited by some with founding the profession of social work.

Chicago's near north side, around Clark Street, experienced a long and wild era that was led by poor intellectuals, artists, bohemians, activists and visionaries and that nurtured feisty phenomena such as Bughouse Square and the College of Complexes.

Here in Chicago is where we find the academic Saul Alinsky studying the mob, and then applying what he learned when he practically invented the idea of community organizing as a way to tip over the power imbalance between the haves and have-nots.

And there's Martin Luther King, Jr., who frequently said that, "The salvation of the world lies in the hands of the maladjusted." MLK marched in the streets of Chicago.

Having grown up in Chicago, I was personally influenced and inspired by the stories of these innovative social change movements and leaders.

All of this community organizing for social change was by and for the poor and powerless, with crucial assists from the well-to-do. These efforts by the underdog all had something in common: As downtrodden as these poor people were, their movements were built on victories. These stories of social change "wins" became a

community memory to guide them on the path in-between oppression and exhilaration. These stories enabled people to recognize the potential of their power for the first time.

Community organizers have a phrase for these victory stories. They call it *organizational mileage*. Each win makes it easier to build the organization, making further wins possible, and creating a mutually supportive positive feedback loop.

What are our “wins” for the 33-year-old-social-change movement led psychiatric survivors and mental health consumers? How can we have more “wins”?

What are a few of the underlying, and often times, contradictory principles?

While this paper cannot inventory all successes, what are some of the highlights in our movement’s stories that promise sustainable and effective growth?

How can we win the non-violent revolution of self-determination and empowerment that Justin Dart, Jr., who is considered to be the father of the Americans with Disabilities Act, who fiercely believed in our movement, called for so often?

Community organizing and social change among psychiatric survivors and mental health consumers become far more effective when leaders learn the underlying principles and specific methods that have fueled our own past victories. Our history is often obscured, scattered and silenced. Despite these obstacles, there are examples and voices in the history of the “mad movement” that provide powerful lessons.

Our past has become a familiar story to some people in this field. This story needs to be told once more, for those both familiar and unfamiliar with it, with an eye to the context that helps lead to these “wins.”

## **II. Brief History: When You Start a Movement, Timing is Everything.**

Successful community organizing probably goes back to the origin of psychiatric facilities. Ever since the first lock locked, mad people have worked together to find a way around it. There were moments of touching camaraderie and bold escape plans.

The impact of some of the earlier organizations and leaders in this field seems fleeting. Consider the 19<sup>th</sup> century crusaders John Perceval (founder of Alleged Lunatics' Friend Society), Elizabeth Packard and Elizabeth Stone. Each of these three leaders followed the same pattern: (1) An abused psychiatric survivor wrote one or more heart-rending books. (2) The author helped organize a society to change the mental health system. And (3) each group faded. One exception is 20<sup>th</sup> century crusader Clifford Beers who experienced abuse in the psychiatric survivor, became an author, and founded what is now known as the National Mental Health Association.

One more chance to create sustainable change seemed to spring out of nowhere in about 1970, when, indeed, there was “something happening here.” Psychiatric survivors somehow began finding one another. We held small conferences. We put out publications, held protests, and formed activist organizations, some of which have lasted to this day (e.g., “We Shall Overcome” in Oslo, Norway was founded in 1969). So what happened in about 1970?

The civil rights movement of the 1950's and 1960's combined with the anti-war, anti-poverty, youth and other early movements. This helped trigger a tsunami of self-determination, sometimes veering to self-destruction, that swept the world, and inspired all kinds and colors of people. By the early 1970's, social change movements seemed to emerge from nowhere, as everyone appeared to be organizing: gays, lesbians,

disabled, women, poor, peace, environmentalists, academic and professional groups, and more. In a way, the Mad Pride of this heady whirlpool helped launch the “mad movement” of the psychiatric survivors, and also helped launch a counter-revolution.

While that term “mad movement” is not used by all or even most participants to describe this social change work, I am using it as a plural in the title because it has a double-meaning. I am also referring to the often contradictory, complex, and twisting paths our social change movement has navigated in 33 years of social change.

When early organizations such as Project Release, Mental Patients Liberation Front, *Madness Network News*, Network Against Psychiatric Assault, and the International Conference on Human Rights and Against Psychiatric Oppression networked in those pre-Internet days, it just seemed natural at the time.

When concerned mental health workers and people with psychiatric diagnoses began collaborating to change the mental health system, it seemed natural at the time.

When Soteria House creators hypothesized that there were advantages to providing non-professionalized mutual support between peers (both labeled and non-labeled), compared to the more traditional psychiatric institutionalization and heavy drugging, it just seemed natural at the time that they would create model alternatives.

But that feeling of effortless actually took a lot of effort. Other successful change movements helped provide the role models, the community newspapers, the skeptical attitudes, the hope, the moral support (which might now be *called technical assistance*), the meeting spaces, the methods of meeting, and – too infrequently -- the grant money to help get these projects off the ground. This synergy led to any number

of successful projects, such as legislation regulating electroshock, public education events, protests, books, poetry, art work, conferences, publications and more.

These other social change movements did not provide Five Star Hotels and international travel, as more established sources sometimes can. These other social change movements gave us something more valuable such as advice, often in their own materials, about how they overcame many of the same hurdles we are facing. These other movements can sometimes provide that support whether or not they understand every single one of our issue and positions.

A lesson from the early days of our movement is that our center of gravity was not the next government grant, it was with among other social change movements led by people of color, women, and different cultures internationally. This was not a matter of political correctness. This was a matter of mutual support and survival.

In a development very similar to what happened with the anti-poverty movement of the mid-1960's, in the mid-1980's the ex-mental patient movement continued to slowly grow, and then began to attract attention from federal and state officials who understood the necessity of self-determination to assist de-institutionalization. The government began to provide a small amount of funding to hire some of the "psychiatric survivors" and "ex-inmates" (who were at this time renamed "mental health consumers"). This funding led to the very popular Alternatives Conference, which sometimes brings together more than 1,000 psychiatric survivors on a nearly annual basis. Government-funded drop-in centers, peer support groups, newsletters, residences, national technical assistance centers, teleconferences, and advocacy organizations sprang up.

When it began, this government funding caused controversy among the more hard-line activists, who called for a boycott of system funding. However, this ill-fated boycott is an example of why other social change movements can provide us with technical assistance. If we had been able to gain the expertise of, for example, the anti-poverty movement, we would have understood that it is a very difficult boycott, indeed, to ask poor people to boycott money. This government funding may have been problematic, but it was necessary and inevitable as our social change movement grew.

However, just as we could not imagine an environmental activist movement entirely funded by the U.S. Environmental Protection Agency -- as crucial as the EPA and its various projects are -- so many leaders need to understand the need for a self-funded and independent movement, too. Both the disability movement and our movement are largely made up of poor people and thus there are few independent, self-funded groups. Several of these independently-funded organizations grew in the 1990's:

### **III. Issues & Problems Today: Dancing to Chaordic Themes**

Psychologist, psychiatric survivor and author Al Siebert specializes in the subject of surviving and even thriving during and after horrible catastrophes such as mountaineering accidents and deadly earthquakes. Al has written that it appears to him that people diagnosed schizophrenic, such as he and I both were, seem to often have special skills for survival, because we seem to be capable of embracing two polar opposites views at the same time, without letting this paradox overwhelm us.

While I'm at first tempted to both agree and disagree with Al at the same time, I'll just say seriously that I hope he is correct. Whether true or not, some of the underlying

principles and challenges of successful social change in our movement do seem to at first to be contradictory.

Let's use an example that is famous in this movement, and often puzzling to those new to it: *Language*. When a fairly powerless constituency is capable of guiding the federal government in its use of language, this certainly qualifies as an example of successful community organizing for social change. In the mental health field today, we are now far more likely to encounter various types of inclusive "people first" language. Let's look at that a little deeper. Language is all about relationships.

Our movement has been strong enough to assert ourselves – as other movements such as the Gypsy or *Rom* people have – to change what we prefer to name ourselves. In the 1970's, activists stressed their connection to the prison justice movement and made a point by referring to anyone deprived of liberty – whether in a psychiatric facility or nursing home – as an *inmate*. In the 1980's, newsletter editor Alice Earl promoted the use of the term *psychiatric survivor* for an explicitly political reason: Alice hoped that each use of the term *psychiatric survivor* would be another opportunity to help remember people who died unjustly in the mental health system.

Government funding necessitated the use of another term, and funders apparently chose "consumer." This movement didn't settle for *consumer*. They bred a hybrid: *mental health consumer/psychiatric survivor*. Although *consumer/survivor* sounds like what many of us feel like on December 25th, the name has stuck

Some have then modified that further to *c/s/x* (Consumer/Survivor/eX-patient); and now still further to *c/s/x/r* (adding an r for Recovered), etc. Use of the term *psychiatric survivor* has persisted, despite controversies such as an angry guest column

in *Psychiatric Services*, that led to the largest number of letters ever submitted to – and printed in – that publication, which is published by the American Psychiatric Association.

No words are perfect. The word origin of *perfect* implies completion, an end-point... and no being while living is finished. Yet the fact is a number of people have somehow united and expressed a preference, which is an empowering act. When others use the term, it implies some level of recognition and respect.

Reflecting the fractal nature of chaordic organizing, as we have seen, this unifying act ended up with more than one single word. Linda Morrison wrote about this in her recent graduate school Ph.D. thesis, which this author has found invaluable:

“Claiming voice is itself a contentious process. When there is no central ‘authoritative’ voice that claims to represent or dictate to a membership, then the process of maturity of the movement will enable different voices to take shape and claim their right to speak, changing (and challenging) the movement over time. I believe this process characterizes the c/s/x movement as a movement that emphasizes claims to voice and also claims to self-determination. This is why the so-called “language wars” (both inside and outside the movement) are so important. ... Who has the right to speak? Who has the right to define?”

There we stand, between asserting ourselves clearly and listening to diverse voices. Self-determination has led us to define ourselves, but also to be open to various definitions. This is where self-determination is chaordic: The edge between “chaos” and “order.” This edge is dynamic, ever changing, risky. And yet, it is on this edge where this movement lives. We in this movement issue a clarion demand to be called a certain name.... And when we approach closer we find a confusion of diversity within.

On the one hand: We need to respect and include the multitude of often-insistent diverse voices. Perhaps a sense of being excluded in the past has led to a fear by



leaders of ever excluding or saying “no” to any voice, at any time, anywhere. This might explain why we have chosen so many terms to describe ourselves.

On the other: There is a need to have a strong structure in order to sustain these organizing efforts, resolve disputes, meet in a harmonious way without disruption, take leadership and create state-wide, national and international organizations with disciplined chapters and sub-chapters.

I’ve chosen three general chaotic themes to illustrate the issues and problems that we seem to frequently face in developing successful community organizing.

(1) POOR MONEY: Groups run by poor people desperately need funding, but with funding they risk losing one of their most precious intangibles: independence.

(a) On the one hand: Our movement is actually one of the larger organized constituencies related to the disability movement, which is in turn one of the more activated parts of a much larger movement that is seldom named today: *The Poor People’s Movement*. Organized poor people with their own funding are very powerful.

Cesar Chavez emphasized the necessity of self-funding among poor people. He told his followers over and over that poor people would get the kind of organization they are willing to fund themselves, so that they can maintain their independence. The State of California did not pay for the California Grape Boycott. With independent funding one is free to be specific and name the names of individuals and groups who are actively working to attack our basic human rights. In fact, the membership of such an organization often vehemently insists that this kind of human rights activity take place.

(b) On the other: Poor people by definition need money, especially to do something as expensive as staff an office, travel hundreds of miles, attend a

conference, and more. Of course government and mental health funding will be – and should be – provided to client-run activities and empowering alternatives.

(2) **PASSIONATE MUTUAL SUPPORT:** Is our long-term goal to fight for a mutually supportive society, or is our method today to be mutually supportive?

(a) On the one hand, each day psychiatric survivors, mental health consumers and others seeking to change the mental health system fight hard, compete for resources, argue, and struggle to lead some pretty tough activism. When an individual feels rage, they may sometimes express that very quickly, directly & angrily.

(b) On the other, we joined this movement partly because we found solace and support, to read poetry, play songs, and hold and support each other. We may prefer the harmony of a support group to the agony of activism.

(3) **MY WAY — TOGETHER:** We use terms indicating “self-“empowerment but the origins of this movement used terms describing “group” empowerment. Which is it?

(a) On the one hand: We may prefer to be in a separatist group of psychiatric survivors and mental health consumers. Or we may even prefer to work totally on our own as an individual completely independent from anyone else.

(b) On the other: We have not done it alone. What has sustained this movement has been group activity. What launched this movement was actually the connection to other social change movements and even concerned mental health workers and the general public. It is not well known that the radical newspaper *Madness Network News* was started in collaboration with mental health workers and the Social Service Employees Union (thanks again to Linda Morrison, Ph.D. for this information).

#### **IV. What Works: Ten Examples of Victories We Ought to Celebrate**

In community organizing, we say that if we are serious about the long haul – really truly serious – we will celebrate each small step on the way.

There are a number of issue “wins,” organizational “wins,” and movement “wins” that reflect the above chaotic principles, and their often-fascinating contradictions. Of course, in this limited space, these are a showcase and not a catalogue. These examples are meant to illustrate the way our mad movement draws upon often contradictory elements, to walk the line between chaos and order to victories.

(1) Board representation: While many people use the word *token* to describe the first representative of a served constituency on, for example, a mental health system advisory board, there could be another word: *pioneer*. Today, there are hundreds of boards where it is assumed that at least one individual – and often more than one – is a psychiatric survivor. Here is a contradiction: Co-optation vs. actual control. And yet hundreds of consumer/survivors have circumvented that challenge and together have produced the recognizable beginnings of a sea change nationally and internationally. We have successfully adopted the disability slogan, “Nothing about us, without us.”

(2) User-Run Community Centers, Peer Support Groups: Clearly, one of the most visible victories is the existence of community centers (e.g., drop-in centers), peer support groups, residential programs and other services that are more or less run by a board emerging, to a greater or lesser extent, from the people who are served. Some observers disparage some of these centers as “Coke & smoke,” where people sip soda and suck on cigarettes. But to some extent these community-gathering places – these safe places run by us – provide a sanctuary for community building. When the time

comes – when there is a bill in the legislature, a need to protest – here are the mutually supportive teams ready to move and fill the seats on the bus or in the legislative hearing room. There is a parallel here to the black church in the civil rights movement: Not all churches were ready to move (some churches were “dry as dust” as MLK said), but the black church in general provided the sheer people power to push to the next level.

(3) Oral history: There are now a number of projects to document the stories and lives of psychiatric survivors. Stories have always driven social change. Oral history helps people learn to tell their story. What appears to be an individual victory of just telling a story often emerges from the context of movement support.

For example, psychologist and psychiatric survivor Ron Bassman triumphantly told his story of survival of insulin coma therapy and full recovery following a diagnosis of schizophrenia. However, as Ron explains, his individual voice has been strengthened by our movement’s support. So what is an oral history – just one lone story? Collectively, the thousands of stories now recorded and exchanged are providing an unprecedented grassroots truth telling that will last to the next generation or more.

(4) The National Association for Rights Protection and Advocacy (NARPA) holds an annual conference that was usually identified as primarily composed of attorneys and advocates working on mental disability law. During the 1990’s, NARPA more typically became identified as primarily psychiatric survivors and mental health consumers, many of whom happen to be advocates and attorneys.

While fairly small, NARPA has successfully sustained its independence. Technical assistance from attorneys and advocates in the group has helped it steer through treacherous periods of bylaws changes and leadership transition that have

destroyed other organizations. Also, by focusing on an annual conference they have developed the skill to use the event to raise funds for their annual independent budget.

Here is the chaotic line: On the one hand psychiatric survivors moved forward to gather on the edges, then the center, then the majority of NARPA's leadership. On the other hand, the assistance of allied attorneys and advocates provided a safe place for activists to meet, while at the same time that government funding and infighting destroyed many other activist-oriented separatist psychiatric survivor organizations.

(5) MindFreedom Support Coalition International (which I direct) had its first coalition meeting in 1990, building on three years of a small publication. We have attributed our sustainability to uniting the goals of mutual support with activism: Mutual support is not just our goal, it's our method to reach our goal. We directly address the tragically common problem of infighting in our movement. While there will always be arguments, and none of us are immune, MindFreedom's board and other leaders have emphasized conflict resolution skills such as making up and moving on, and the use of mediation. If an individual is unwilling to resolve a dispute or do mediation, the board of directors has an ethical duty to ask the individual to leave the organization.

Just a few examples of our successful campaigns:

- We broke the silence about the existence of involuntary electroshock against the expressed wishes of the subject.
- We used peaceful protests to educate the public about human rights violations in the mental health system.
- We used cultural events such as "Mad Pride" (each July 14) to celebrate our social change movement. See more victories at [www.MindFreedom.org](http://www.MindFreedom.org).

(6) California Network of Mental Health Clients: CNMHC led a three-year campaign to stop involuntary outpatient commitment in the state legislature. Even

though the bill eventually passed, the hundreds of mental health consumers and psychiatric survivors involved held the line, inspired thousands of activists, and educated millions of people about these issues. CNMHC worked closely with non-survivor advocacy groups and other allies. While CNMHC is government funded, they nevertheless upped the ante by co-sponsoring a protest of the American Psychiatric Association on the issue of choice, when the APA met in San Francisco in May 2003.

(7) Breakthrough to the disability movement: For 33 years, our social change movement leaders have seen themselves as embedded in a number of social change movements that might be seen as following the dream of Martin Luther King. For instance, one of the first constituencies psychiatric survivors identified with was prisoners working to reform the prison system. For many years, psychiatric survivors tried to be included in other social change movements such as women's organizations, labor, and even environment. This was often frustrating, since even progressive groups tend not to have a deep understanding of our constituency, our issues, and our goals.

However, several breakthroughs did occur with the disability movement. The path to this victory is chaotic: There are people in our movement who accept their psychiatric diagnosis ... and there are those who do not believe in their labels, or consider their labels to be their only disability. The disability movement itself is diverse, big and experienced enough to see past these differences, because they themselves have a deep chaotic edge on being pro and con medicalization, themselves.

One example of this disability bridge-building was the long-term work of Rae Unzicker and others in the National Council on Disability, which is the highest disability organization in the US government. Utilizing NARPA as a place to gather testimony of

survivors of human rights violations in the mental health system, NCD officials created a small book that serves as a virtual blueprint of many of the goals for self-determination.

(8) United Nations: Partly as a result of the victories with the disability movement, people diagnosed with psychiatric disabilities are now represented in major human rights meetings in the United Nations. This synergy helps provide psychiatric survivors with credibility. The individuals who have represented our movement in the UN have mainly been brand new to this particular venue, but have used their skills from our movement to make new friends with leaders in the UN and in Non-Governmental Organizations (NGO's). MindFreedom became a registered NGO. Our movement did not wait to have a million-dollar organization before entering the UN playing field: We just walked inside, in our own way, and made friends.

(9) Defending the psychiatric survivor/mental health consumer movement from direct attack: For 33 years, the social change movement led by psychiatric survivors and mental health consumers has largely been ignored by larger institutions and entities. A sign of the growth and maturity of this social change movement is that a few individuals and groups apparently feel threatened, and are directly attacking our movement and its values. A further sign of growth and maturity is that this movement is increasingly developing the ability to notice such attacks, track them, discuss them, and respond in a civil way that can actually turn out benefiting social change activities.

(10) Links to the youth movement: This mental health advocacy is, as we know, a very difficult field. Sometimes it seems as if decades of experience and knowledge are needed. At the same time, activism by youth themselves can also seem like an uphill

fight. After all, youth is a state of being that is inherently temporary. However, there are youth leaders who are speaking out, writing, and guiding change in mental health.

According to youth leaders I've spoken with, the youth culture itself seems at times to be dispirited. For example, youth suicide has increased dramatically in the last few decades. Many youth say they are hesitant to step forward and lead for fear that other youth may attack them as being authoritarian, uncool or "too hopeful." Slowly, at the edge of our movement, youth have been able to assume leadership. More and more youth are speaking at conferences, including at events for and by youth. They are writing articles, using the Internet, and putting out "zines." In their own way they are beginning to assume the leadership of this movement, because of course one day it will be theirs to lead. Where will they lead it?

#### **V. The Chaordic Path to Nonviolent Revolution**

I edited the draft of this paper from the location of a hunger strike I participated in called the Fast for Freedom in Mental Health. Six of us at "hunger strike central," along with about 17 solidarity hunger strikers, protested human rights violations in the mental health system. We especially pointed out what we see as a lack of adequate choices for families with members in extreme crisis, because of undue influence from the psychiatric pharmaceutical industry in the mental health field. I fasted for the first 13 days of what turned out to be a 22-day hunger strike.

The organizing of this hunger strike, led by social worker Mickey Weinberg, built on the power of mutual support. The atmosphere in the two-story old school where we held the strike was charged with passion. We could feel our mutual support for each



other build and we could feel how hundreds were taking action in support. This spirit of direct activism won major local, national and international media.

A paper about victories in community organizing in the mental health system is personal to me. The synergy I describe in this paper is not just theoretical. I felt it.

One moment I will always remember: We held a news conference on Day 3. Surprisingly, a wide range of media showed up. Six of us psychiatric survivors sat behind one end of the table and spoke to the media about our personal stories. And then three members of our 14-member scientific panel who were sitting behind the other end of the table weighed in. I could feel the synergy of psychiatric survivors working together with dissident mental health workers. One group had personal credibility, and the other group had professional credentials. We had far more effect together than when either group worked alone.

Today, there are many scientists, academics, clinicians, mental health workers and others who are working for a nonviolent revolution in biology and throughout the sciences. These leaders are showing that the principles our movement has stood for — self-determination, empowerment, mutual support, recovery and more — are rooted in the complex mysteries of life, biology, the immune system and the mind.

For me, many of the lessons of yesterday and today in our movement are about the importance of mutual support both on the micro-level of individuals, and also on the macro-level between social change movements. We need to learn from other social change movements about what has worked in the past. We need to turn to other social change movements to learn about what is helping them today.

We've learned in our own movement that violations like forced interventions may seem to work in the short term, but forced interventions have unpredictable and sometimes even deadly results on the subject, especially in the long term. We understand that support and empowerment are crucial for own recoveries.

The value of this self-determination is also true when it comes to changing complex systems such as societies and professions and industries. We cannot absolutely predict what these entities, and the individuals running them, may do. However, we can organize the strength in numbers, the mutual support of other movements, and the underlying principles that it takes to have a powerful, peaceful effect. We've learned – just as the movements for peace, women, environment and many more have learned over and over – that what appears to be a fairly small influence may have an unexpectedly profound sway on our future.

Mahatma Gandhi called this *soul force* or *satyagraha*.

So while we cannot absolutely predict where we are going, we can resolutely state our founding values, and reach out to a wide diversity of the public. We know we need to learn from other social change movements. One thing they have taught is that nonviolent, bolder, direct actions have been used by almost every movement.

I have frequently pointed out that the roots of the words “patient” and “passion” have the same meaning: *to bear suffering*.

Our social change movement lies at a crossroads.

Do we choose to patiently experience — and sit by patiently while others experience — the severe human rights violations, the choking poverty, the forced drugging, shock, restraints and humiliation? Do we stay in the role of mental patients?

Or do we choose to face this heartache with passionate activism, as empowered and free actors who are capable of writing our own roles for how we wish our lives to be lived? Do we affirm our role as human beings, interconnected and equal to all others?

The passionate force of thousands of hearts and minds united is more than theory. I've felt that force in this movement. I felt it in the hunger strike. We are part of a long line of people who have sought to redeem our own society. I quoted Martin Luther King, Jr. earlier. I end now with a longer excerpt from what he said repeatedly in a number of his speeches and essays,

“Psychologists have a word which is probably used more frequently than any other word in modern psychology. It is the word *maladjusted*. Well, there are some things in our social system to which I am proud to be maladjusted and to which I suggest that we ought to be maladjusted. The salvation of the world lies in the hands of the maladjusted.”

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# Fostering Leadership: Collective Self-Determination Among People with Psychiatric Disabilities

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## **Abstract**

Fostering leadership among people with psychiatric disabilities and identifying strategies to reach more people in regard to collective self-determination concepts are vital to create societal change. Practical engagement and educational approaches can be used to develop interest and leadership among consumers/survivors to be able to effectively address current social barriers to self-determination. Although having different styles and backgrounds, leaders share common characteristics and challenges. They realize outreach, recruitment, and planning are important to the success of an organization or group. There are empowering skill-development curricula available today, such as the exemplary Leadership Academy, which provides practical lessons on leadership and developing shared action plans for positive community change. This paper describes concepts for fostering consumer/survivor leadership, strategies for engaging people in collective self-determination activities, and educational approaches for strengthening collective self-determination efforts.

## Introduction

To create positive systems and community change, grassroots leaders are needed to promote collective self-determination among people with psychiatric disabilities. Identifying strategies to engage more people with collective self-determination activities is vital for continuing positive societal change. Practical educational approaches can be used to develop interest and leadership among consumers/survivors in addressing current social barriers to self-determination.

### Concepts for Fostering Leadership

#### Leaders have universal characteristics and challenges.

Leaders are people who establish a path and help others to move in that direction. Leaders inspire others and help create a sense of mutual purpose. In groups and organizations, leaders guide several followers. In this dynamic of leaders and followers, everyone learns more about themselves and their own abilities. Although having different styles and backgrounds, leaders share common characteristics and challenges.

Leaders take many forms. There is no one perfect type of leader. People who are of diverse gender, age, race, socio-economic background, religion, etc. have become leaders. They all started much the same as anyone might, by growing into leadership, overcoming fears, and taking risks to speak out, to fight back. According to Si Kahn (1991) "Leaders are not born. Leaders are made through experience, work, and training" (p. 22). Fostering leadership is crucial for our communities. To make change, many leaders are needed. Recognizing and supporting people with leadership qualities is actually an essential part of being a strong leader.

Contrary to popular belief, leaders are not born, but often have experienced great losses through which they gain new chances. Some find themselves thrust into leadership positions. This is likened to the shaman archetype who experiences death in order to become the healer. In comparison, the quest of people in recovery may take them into unexpected leadership roles. Moving beyond the humiliation of our past, and throwing away shame, many times allows us to seek help and advice where once we were reluctant.

Leaders are noted for surrounding themselves with people who are “smarter” than they. This behavior evolves from the leader’s desire to serve a cause and not simply himself or herself. An actual example from the West Virginia Mental Health Consumers’ Association involved the CEO attempting to explain the work they did. At first he was at a loss because the consumers’ organization was so new and rapidly growing. Every day involved grassroots efforts, building in a flurry of activities. Yet, he knew for the organization to show its successes it would be necessary to provide service data and outcome measurements for peer services. At the time, this was virtually unheard of. He brought together a consultant and several innovative staff members. Together, they worked to identify a process and to generate a measurement template. This combination of additional expertise and the leader’s vision helped to sustain and further the organization.

Kahn lists twenty personal qualities of a leader in his book, “Organizing: A Guide for Grassroots Leaders”. In this writing (pp. 25-27), Kahn states that a good leader likes people, is a good listener, makes friends easily, builds trust easily, talks well, helps people believe in themselves, lets others take the credit, works hard, doesn’t get



discouraged too often, has a sense of her or his own identify, asks questions, is open to new ideas, is flexible, is honest, is self-disciplined, mature, sets limits, is courageous, has vision, and has a sense of humor.

It makes sense that leaders are often around people. Thus, it is essential for a leader to be able to engage in discussions, to listen, and to work well with others in joint activities. People put their trust in leaders and are willing to take personal risks on their behalf. Being trustworthy, honest, and able to understandably explain things is important. Having self-confidence and the ability to share successes is a sign of a strong leadership. Leaders are self-disciplined; they work hard and long, even when progress is slow. It takes courage to move forward. To be effective, they handle their disappointments and look to the future, secure in who they are. Leaders get others to think and speak by asking questions. In turn, leaders grow by being flexible and open to ideas and suggestions of others. They stick to the vision of making the world a better place. This can be trying at times and maintaining a sense of humor helps.

Once such instance occurred in a psychiatric hospital where consumers were advocating passionately for a seat on a research committee. The attending physician, heading up the research effort, was vehemently against it. His rationale included statements suggesting consumers only knew how to talk about themselves and certainly didn't have research-related skills. In response a consumer leader put forth a series of questions. "Who is on the committee now?" "What are their academic credentials?" "How is confidentiality handled?" "Have you ever worked with consumers conducting research?" "Do you realize many of the consumer representatives at this table have more education than your existing team?" After fumbling and failing to

provide plausible answers, the physician finally came to a new conclusion. He eventually knelt by the speaker and asked, “how can we work together in this research?”

In addition to qualities of leadership, there are needed skills. Skills are learned behaviors that can be mastered over time. The best way to learn is through experience and to focus on developing a few skills at a time. Some skills suggested by Kahn (1991, pp. 28-29) include: working with people, defining issues, holding effective meetings, understanding organizational dynamics, creating strategies, raising money, conducting research, maintaining communication, dealing with media, setting up trainings, understanding culture, developing coalitions, understanding politics, speaking publicly, and supervising staff.

This list of skills can be intimidating to the beginning leader. Strengthen the skills one knows one has by applying them. Identify areas to improve. Go to trainings and read relevant books. Get involved by working on a few skills at a time and connect with other leaders having those skills. Ask questions.

In addition to qualities and skills, leaders face challenges. Three common challenges for leaders are managing power, handling the workload, and dealing with the personal pressures involved in representing an organization.

Power of a leader is to be used to build power within the people represented, not for the sole gratification of a leader. It is easy to be affected by the status of being a leader. Meetings with top brass, television spots, speaking engagements etc., can cause an inexperienced leader to think more of himself or herself rather than the organization represented. When power becomes self-serving, it is being used

irresponsibly and will have negative affects. Unfortunately, time after time, people coming from an oppressed environment take on characteristics and roles similar to their former oppressors. This happens in the consumer/survivor movement. Some people use a totalitarian approach from fear of losing ground or desire for power and control. This often results in leading no one. To lead, one has to have followers.

At the same time, any grassroots initiative requires vigilance and hard work. Often leaders put in long hours, becoming overworked. They give up free time and family time, which can lead to personal difficulties. As an organization grows, more and more time is demanded to oversee activities. Delegating responsibilities is crucial to avoid stressful results. Without delegation, a leader trying to do it all may become resentful of staff, which causes additional difficulties. In contrast, working little and occasionally checking in, while expecting staff to handling everything creates problems. Discovering a time-frame that works on a long-term and regular basis is beneficial. Otherwise, burnout can occur.

Organizing is emotionally charged. Even with the best of skills, dealing with personal pressures can be overwhelming. Leaders have had marital problems, alcohol and drug abuse, stress and burnout, to name a few difficulties. As organizations grow, leadership can be criticized, challenged, and ridiculed by others. Sometimes there are physical threats and just plain being overworked and exhausted. Kahn (p. 44) gives five tips for managing these pressures. Try to avoid overwork. Set goals that are reasonable and manageable. Develop a personal support system. Preserve time for yourself. Take time to celebrate. Role-model self-care for others coming along. Leaders have an obligation to their followers.

As suggested by Kahn (1991), Kouzes and Posner (The Leadership Challenge, 2002), agree that ordinary people become leaders. They also note that with practice ordinary people can do extraordinary things. In their study of the dynamic process of leadership, they have discovered five practices that are common to personal best leadership experiences. These practices are accessible to anyone and have stood the test of time. Best practices for exemplary leadership, according to Kouzes and Posner (2002) are to: model the way, inspire a shared vision, challenge the process, enable others to act, and encourage the heart.

Modeling the way is about practicing what one preaches. It fits with the old adage: walk the talk. This builds respect. True leaders clarify their values and stand up for their beliefs. There must be consistency. It is important to align actions with values, showing commitment. Followers are often attracted to the leader first, then the plans. Shared values make strong organizations.

Inspiring a shared vision is about creating a common sense of future. Leaders promote vision and what might be. Leaders are forward-looking. This involves knowing about the dreams and hopes of others and having peoples' best interests at heart. They are passionate and enthusiastic about vision and values. Envisioning the future and enlisting others strengthens an organization and supports collective self-determination.

Challenging the process consists of taking risks. Leaders rise to the occasion and find ways to make transformations. Problem-solving is a big part of challenging the process. This might consist of developing creative programs, participating in legislative change, redesigning organizational structure, or starting a new business. This principle

supports the idea of stepping out, taking a chance. Recognizing good ideas from the people on the street, in direct service, at the grassroots level is where innovation starts. Listening is essential. There may be failures as well as successes. Each provides an opportunity to learn and grow.

Enabling others to act involves team effort. An interesting test for potential leadership described by Kouses and Posner (2002) after interviewing thousands of personal-best cases, is “the frequency of the use of the word, we.” Collaboration and trust-building are important in applying this principle. Everyone involved in a project has to be engaged for it to have excellence. Leaders work to make others feel “strong, capable, and committed”...“when people are trusted and have more discretion, more authority, and more information, they’re more likely to use their energies to produce extraordinary results” (2002, p. 18).

In managing groups and organizations, a leader may not have time, interest, or inclination to deal with every tiny detail of program operation. This is where teamwork is essential. When employees, volunteers, and/or followers keep their eye on the vision, wondrous things can occur. The CEO of the West Virginia Mental Health Consumers’ Association recollects many instances where he has entered his office with an idea, but no plan. By turning to his managers, proposal writers, and/or volunteers, he has gotten results. He mentions seeing excitement in people’s eyes as a connection and “aha” is made. From that point on, discussion is focused on possibilities for implementation of the vision. However, if interest and commitment is not present, the vision can be lost to uncertainty and hours of unproductive dialogue.

Encouraging the heart exhibits genuine acts of caring. It's about continuing on despite challenges and disappointments. It's also about showing appreciation for people's accomplishments and celebrating successes. This can be as simple as creating handwritten note or detailed as sponsoring an honors banquet. Rewards are linked to performance. Leaders make sure that works improving the organization are highlighted. Celebrations can build common identity and increase community spirit. Leaders can develop and maintain their leadership skills.

Much like Kahn (1991), Kouzes and Posner (2002), Bobo, Kendall and Max (2001) agree that leadership is developed. Furthermore, they suggest that to listen and figure out "what the potential leader's self-interest actually is and then shape the position in ways that help the leader achieve those personal goals" (p. 123) is a good strategy for organizational success. A common way for leadership to evolve is through volunteerism and committee work. Committees have tasks to accomplish and strong leadership helps get the job done. Subcommittees give people opportunities to develop leadership skills. Give new people jobs to do and celebrate their successes. Leaders break big jobs into small pieces and get someone to help with each piece. This also supports collective self-determination.

One way to maintain and grow leaders is to practice evaluations and feedback. Take time to offer helpful hints and constructive feedback. After meetings some groups hold a brief evaluation session. Sometimes this is written, sometimes it is verbal. Wrap up time at meetings is also a great opportunity to praise accomplishments and to recognize hard work. Feedback can be provided by a group and/or it can be given by a fellow worker, mentor, or coach. When done in a caring way, feedback can be

invaluable to the person who is eager to apply new learning. Certainly, routine personnel evaluations are opportunities to explore ideas and concerns and to develop helpful action plans for increasing leadership skills.

Again, one of the most effective ways to evaluate performance is to utilize a feedback loop. Using this method in a non-threatening manner to mentor people helps build confidence. Borrowed from training and development programs, feedback loops can be helpful to people in recovery who previously might never have thought of themselves in leadership roles.

Bobo, Kendall, and Max (2001) promote the concept of “rotation of roles and developing systems for training people for new roles” (p 124). They suggest very few individuals want to stay in the same role forever. It can be an interesting to job shadow, to switch roles with colleagues, and to take charge for a day. In these ways, sometimes, new talents and interests surface. It is also helpful in larger organizations to have people who can fill in for one another. Staff development trainings and providing access to external trainings and educational events keep people involved and growing. Co-facilitation of skill development workshops can also refresh leaders and renew their enthusiasm. It is suggested that using strong, skilled leaders to train others builds leadership development into every position and keeps people from being irreplaceable.

Align personal goals with organizational goals. It stands to reason when people’s personal goals fit with organizational goals, they will be more effective and engaged. Bobo, Kendall and Max (2001) encourage organizations to “ask leaders to set personal leadership development goals as part of your annual goal-setting session” (p. 124). If personal goals are not aligned with organizational goals this can cause

conflict. However, much progress can be made for both the organization and the leader who is supported and trained to reach personal goals that are in line with organizational ones. Leaders are motivated by their feelings and goals. This motivation is a great help in accomplishing organizational objectives when both types of goals are aligned.

### Strategies for Engaging People in Collective Self-Determination Activities

#### Leaders advocate with and on behalf of the people they serve.

Promoting advocacy is one strategy for involving others in collective self-determination. Leaders in the system of mental health care are typically strong advocates. The roots of advocacy, a desire to make a difference, can be traced back to Dorothea Dix, who tirelessly worked on behalf of people with mental illness, and Jane Addams, who began the settlement house movement. These leaders were able to focus on their dreams, hold to a set of ideals, and create positive change in the world in which they lived.

Ezell (2001) states in his text, *Advocacy in the Human Services*, that “it is important to think of advocacy as something one does, an intervention” something beyond “thoughts, feelings, or attitudes” (p.11). Advocacy is a process whereby problems are eliminated and conditions improve for people, communities, and society. Advocates believe people have a right to quality of life, to be free from harm, and to have opportunity to grow. Advocates realize social justice remains a goal and problems are often rooted in social institutions. People want to help.

Advocacy takes into consideration peoples’ experiences and unmet needs. It is a process that can be both exciting and frustrating. Ezell (2001) defines advocacy as “purposive efforts to change specific existing or proposed policies or practices on behalf



of or with a specific client or group of clients” (p. 23). Change is the common factor. Leaders help create change. With their followers, they work to change policies and practices that prevent attaining goals. Every advocate has purpose in her/his efforts. Skills recommended for leaders in advocacy include persistence, tenacity, and patience.

The definition of advocacy does not limit who does it. Those in the mental health movement often refer to being involved in self-advocacy, which is about creating beneficial change for oneself. Certainly, a person with psychiatric disabilities or a group of people with psychiatric disabilities can effectively advocate on their own behalf. As evidenced many times, one person can make a difference. Self-advocacy focuses on individuals and is distinguished by the fact they are doing their own advocacy work. This is what self-determination promotes. Experience gained through advocating for oneself increases confidence and helps in developing leadership skills. Tactics for self-advocacy include such things as letter-writing, requesting a meeting, researching an issue, and asking for better services. People can be supported and encouraged to speak on their own behalf

Systems advocacy is about changing policies and practices that affect all persons within a group. According to Ezell (2001, p. 28), systems advocacy can be considered the same as class advocacy (which comes from the legal term: class action). When people take collective action on their own behalf this is also known as class (or systems) advocacy. Leaders having advocacy experience can help facilitate the empowerment of others. There is strength in numbers. Several advocates can engage in collective self-determination to create positive societal change. Tactics for

systems advocacy include negotiating with agencies, monitoring, giving testimony, and influencing administrations.

As important as advocacy is in serving the class, it is imperative a good leader heralds advocating for those things which are truly meaningful to the people being served. In 1998, the West Virginia Mental Health Consumers' Association gathered two hundred consumers active within this organization. During a two-day period, a list of values was collectively determined and described. These identified values continue to serve the organization as a guide for all decision-making. They are in the policy and procedure manual. A leader in touch with followers honors their collective values. Problems arise when the values of those seeking and needing advocacy are not the same as the leadership.

Community advocacy involves a particular group of individuals affected within a given community. This type of advocacy is about educating the community, defining and documenting problems, and organizing the community to take action. Community advocacy emphasizes changing ideas and attitudes. Tactics for community advocacy include education and media campaigns, interviews, direct contact, and workshops. People involved in community advocacy may not know each other, but have similar problems or needs. Leaders who are community advocates benefit from cultural awareness, a willingness to learn about behaviors and beliefs. According to Ezell (2001, p. 27), "the groups whose cultures are of great concern to advocates are generally those who have suffered the consequences of oppression and discrimination, predominately people with disabilities, women, older people, people who are poor, gays and lesbians, and ethnic and racial minorities." Engaging people in collective self-

determination as evidenced through various forms of advocacy is crucial to create societal change.

Leaders recruit through mutual trust, interdependence, and broad membership. In organizing, “we move from individual to the group” (Kahn, 1991, p. 97). People have to decide they want to be part of an organization and to advocate for change. Leaders build on personal relationships and recruit others who want to make a difference. There is much work to be done to help create a just society. Development of skilled leaders is an ongoing activity.

To lead, there has to be followers. A leader often begins by cultivating a group. Through personal contacts it is easier to tell what individuals are thinking and feeling. Initially it is helpful to bring small groups together. Kahn suggests making a list of people and to decide where and when to see each person on the list. Think of where people gather naturally in order to make contacts. Sites might include churches, school, work, supermarket, barbershop, restaurants, bus stops, bowling alley, etc. In recruiting others, be prepared to answer common questions, be aware of the issues, and how people feel about them.

To foster leadership, look within the organization. Look for people who have shown commitment and reliability. Watch to see who gets along with others, is motivational, and follows up on his or her commitments. Encourage people to work with leaders, to learn the ropes. As others go through the processes involved in leadership, they develop their own leadership skills. It is the sign of a good leader to develop other leaders. Use the principle of direct representation and create opportunities to gain experience.

Leaders recognize people want to put time and effort into useful projects.

Recruiting people and getting them involved is a big part of organizing. It's the way that groups are built and collective self-determination starts. People feel more ownership and commitment when they are part of planning and implementing. They want to know they are involved in activities that are truly beneficial. The simplest technique to get people to contribute their time, effort, and money into projects and activities is to ask them. While leaders appreciate staff efforts, they also recognize that volunteers are a key component of success. Volunteerism is strong in American life. It's a familiar tradition for people to care about their communities and to be concerned about issues. Leaders realize people need to know that their contribution matters. It is important to explain goals and action plans in a compelling way that inspires people toward the vision. As indicated by Bobo, Kendall, and Max (2001), people join organizations to work on issues that personally affect them, for career interests, power, because it's the right thing to do, and sometimes to promote their own interests. Orient others clearly to the mission and activities of the group so they understand how they might fit.

Volunteer groups can be quite effective in gathering in-kind contributions. Volunteer hours, donated materials, and valued resources create an impressive "budget". The volunteers themselves make all the difference as they capitalize on contributed time, energy, and resources. Accelerated growth leads to the need for paid employees. Sometimes an amazing and often troublesome shift occurs when a group based on volunteerism acquires funding. When paid skills are not combined with group values the atmosphere of an organization changes. Early on, the vision is the prize;

later, the paycheck often becomes the prize. This can be challenging to a leader eager to focus on mission, honor organizational history, and return to the original passion of volunteers following a vision.

One person does make a difference. Organizations are built one person at a time. “Often, it’s the action taken by just one person, sometimes someone who has never done anything like it before, that is the spark to set off a major organizing campaign” (Kahn, 2001, p. 19). In effective organizations, each person has a role to play, a job to do. As noted previously, matching personal goals to organizational goals builds success. To engage people in collective self-determination activities, they need to believe they are important to the cause and part of creating change. Each person is unique. Find out their special talents. Some have connections in the community, contacts that might be useful. Others belong to various networks, such as churches, social groups, community organizations that might host a meeting or participate in joint efforts. In contrast, others may be more solitary and enjoy editing reports and producing media releases, writing letters, or making phone calls.

When engaging others, listen to them, obtain commitment and be sure to follow up. Be mindful of building long-lasting relationships for the organization. Get to know people through conversation and establishing rapport. Learn about their interests and concerns by asking questions and providing acknowledgement and support. Tie people’s interests to mission and vision. Organizations have needs that can be addressed by engaging people’s interests and talents. When working with others, it is wise to get a commitment from them. This is part of action planning. What will they do, what additional resources might they need, and when will it be accomplished? When

working with others and developing action plans, follow up. Keep track of people and let them know you are glad to have them involved. Be sure to pay attention to new people. Bobo, Kendall, and Max (2001, p. 117) offer tips on keeping volunteers, noting that, “recruitment has to be backed up by an organizational plan, with clear goals and expectations of what volunteers will do.” They suggest, “getting people to work as soon as they arrive” and to have a “variety of things to do”. “Recruitment is the lifeblood of an organization” and “growing, thriving organizations must train staff and leaders on how to recruit others and build recruitment strategies into their ongoing program work.” It is important people feel their time is appreciated and that they are needed.

#### Approaches for Strengthening Collective Self-Determination Leadership

##### Lessons can learned from psychiatric rehabilitation.

Generally speaking, rehabilitation is about reducing negative affects of psychiatric disabilities in a person’s everyday life. Psychiatric rehabilitation emphasizes and builds “on the healthier features of the person: his or her strengths and interests” (Pratt,et. al. , 1999, p. 38). Recovery from mental illness is the vision of psychiatric rehabilitation whereby individuals find meaning and purpose in their lives, moving beyond their illnesses. Anthony (1993) states that “recovery is what people with disabilities do”.

Embracing the goals and values of the psychiatric rehabilitation approach can be useful in supporting personal empowerment and thus strengthening collective self-determination. According to Pratt (1999) goals include: recovery, community integration, and quality of life. Values include: self-determination, dignity and worth of every individual, optimism, capacity of every individual to learn and grow, and cultural

sensitivity. A key psychiatric rehabilitation principle is that skills combined with supports can bring success. Pat Deegan (1988) suggests that the task for the individual is the creation of a new self-image that incorporates the fact that the person has a mental illness. The task of a group of might be to help create a positive image in the community, raising awareness about the many contributions that people with mental illness can and do make. Deegan (2001) notes that, “recovery is not the privilege of a few exceptional clients”...“we can now tell people the good news that empirical data indicate most people do recover”. With this in mind, it is important to build skills and supports for every person.

Building skills and supports is especially beneficial when working with volunteers in an organization. This may be someone’s first work experience. Vision and values of recovery are often eagerly embraced. A leader understands the initial investment of skills teaching will enhance vision and purpose. Support, as long as needed, will serve the organization well. Skills teaching is one thing, but attitudes (values) cannot be taught. This affects collective advocacy readiness and successful outcomes in the consumer/survivor movement.

Readiness is a factor often discussed in the psychiatric rehabilitation approach. Readiness assessment is about evaluating whether a person is ready to enter into a process that has chance for success. Cohen, Farkas, and Cohen (1992), mention five factors in determining readiness. They include need for change, commitment for change, environmental awareness, self-awareness, and closeness to others. These factors can be related to collective self-determination. How ready is the group to enter a process that has a chance for success? Is there need, commitment, levels of

awareness, and mutual support? If so, there are several possibilities for next steps. One such possibility is taking part in a Leadership Academy.

Lessons can be learned from consumer initiatives: Leadership Academy.

“As consumers become proficient with advocacy skills, they are better able to impact the planning and provision of mental health and support services at the state and local levels” (Hess, Clapper, Hoekstra, Gibison, 2001). This is part of the rationale behind the exemplary Leadership Academy training. The Leadership Academy, begun in Idaho and further developed in West Virginia, is a three-day training for consumers of mental health services that emphasizes empowerment and collective self-determination.

Lessons in the Leadership Academy include such topics as: “Conducting an Effective Meeting”, “Identifying Issues”, “Working with Culturally Diverse Groups”, and “Developing Clear Goals and Plans for Action”. Applying principles of adult learning, which include flexibility, goal-orientation, building on participant experience, and providing practical information, the Leadership Academy shows the participant examples of each lesson, tells step-by-step how to do the activity, and provides opportunity for participants to practice skills in a safe learning environment. There is a graduation ceremony and an expectation that after the Leadership Academy people will continue to network, develop action plans, and work together to create community change. Some examples of staying in touch include quarterly graduate teleconferences, annual leadership conferences, retreats, support groups, and town meetings.

This skill-building curriculum changes the way participants relate to their environment. Through the Leadership Academy, advocacy groups become “empowered



to take action steps designed to significantly affect their environment and the development of the mental health services system". Especially beneficial, as reported by participants, is the ability to network with others, gain support, and increased confidence. In addition, participants felt learning the advocacy skills, leading groups or meetings, and gaining useable knowledge to make a difference in their communities were important parts of the Leadership Academy. "In a 27 months period, graduates took 1,345 action steps to address issues of concern, with 400 outcomes, ranging from the establishment of a speakers bureau to starting a respite facility" (Hess, Clapper, Hoekstra, & Gibison, 2001) Skill development and outcomes are important aspects for leaders to consider.

Sabin and Daniels (2002), describe the Leadership Academy as "a prominent program for strengthening consumer advocacy skills, as a model of skills training and a source of practical lessons on improving managed care and the mental health system itself" (p. 405). Graduates of the Leadership Academy have worked together in writing letters, going to meetings, raising funds, and becoming involved on committees and boards. They have seen outcomes of their collective self-determination, such as opening a respite care facility, development of anti-stigma education programs, and forming coalitions. In West Virginia, graduates of the Leadership Academy help to strengthen the statewide consumer network, hold quarterly conference calls, conduct trainings, and host a Leadership Academy conference. This helps to link the graduates in common initiatives. Consumer voice and ongoing support are basic to the Leadership Academy. As suggested by Sabin and Daniels (2002), follow-up networking activities reinforce learning and support its application.

Lessons can be learned from consumer initiatives: Mental Health Recovery Education and WRAP.

Support, hope, advocacy, self-responsibility, and education are key concepts of recovery, according to Mary Ellen Copeland (1997), founder of Mental Health Recovery Education and WRAP. WRAP is about wellness recovery action planning. Creating positive change starts one person at a time. WRAP is a self-maintenance strategy that helps people to manage their symptoms and incorporate ways to stay well. Based on values of choice, respect, and dignity, mental health recovery education and WRAP has been shown to improve self-esteem and coping skills, while reducing crisis and feelings of helplessness and hopelessness. With renewed faith in self, leaders are emerging who tell compelling stories of how they have had a turning point in their lives and give a message of hope and recovery.

Mental health recovery educators, working from ethics and values as described by Mary Ellen Copeland, are teaching others and building networks composed of various stakeholders in the system of mental health care. This approach takes one from attention to personal self-determination to discovering the benefits of collective self-determination. Mutual support and interdependence are encouraged by WRAP participants in order to move forward, addressing challenges and celebrating successes. There is now an emphasis on using mental health recovery education and WRAP in organizational development, providing instruction for systems of mental health care, including service providers, educators, consumers, and consumer supporters, etc. Leaders are encouraged to participate.

Lessons can be learned from consumer initiatives: Advocacy Unlimited, Inc.

Based in Connecticut, Advocacy Unlimited, Inc., (AU) is an organization that is dedicated to promoting self-determination for persons with psychiatric disabilities or people who are in recovery. Advocacy Unlimited holds the “belief that individuals with mental health disabilities should have the full rights, opportunities and expectations for a meaningful and personally satisfying life afforded to all members of society” (Advocacy, Unlimited, 2003, online). To accomplish this, AU has an advocacy education program that teaches skills for consumer leaders that can be applied in shaping policies and services. In the spirit of collective self-determination, AU’s strategy is to develop a network of educated consumer advocates through the state of Connecticut.

Advocacy Unlimited, Inc.’s advocacy education program consists of an intensive fourteen week semester, with a seven hour class each week. After graduating, advocates attend bimonthly classes to help support their efforts. Participants commit themselves to volunteer six hours a week for six months at an agency or clubhouse of their choice. While there, they arrange presentations and workshops relevant to advocacy. Skills learned in this program are applied toward system change. Advocates form an empowered network interested in working together to shape policies and services relevant to their lives. Outcomes provide strong evidence of the power of collective self-determination.

Lessons can be learned from consumer initiatives: Alternatives Conference.

Leaders value opportunities to improve their skills and learn new information. Attending educational gatherings, meetings, workshops, conferences, and classes are all venues for increasing knowledge. Not only do leaders attend seminars, they teach

them. One of the important tasks of a leader is to nurture new leadership, which can be done by providing educational and skill-building opportunities.

Once such learning opportunity is the Alternatives Conference, which has been in existence nearly twenty years. According to the Center for Mental Health Services, which helps to fund the conference, it's purpose is to provide a national forum for consumer/survivors to meet, exchange information and ideas, and provide and receive technical assistance on a variety of topics of interest. It transfers knowledge on best practices in mental health and support services. The information and knowledge gained at the Alternatives conference can help consumer/survivors to advocate for effective individual treatments and services, as well as for broader care and service system improvements.

Attendance at Alternatives has averaged nearly 900 participants who represent states across the nation and occasional visitors from other countries. Institutes, workshops, caucus events and plenary sessions are all part of this event. Participating in events, such as Alternatives, is a significant way to learn from people with life experience who are making a difference in the system of mental health care. Participants range from founders of the consumer movement to people who are attending for the first time. In this instance, knowledge is power. People have opportunity to network, share ideas, and learn new skills. Collective self-determination among people with psychiatric disabilities is evident in the planning and implementation of a national conference such as Alternatives.

### Conclusion:

Leadership can be fostered by recognizing there are common characteristics and challenges for leaders, leaders have an obligation to their followers, and that leadership skills can be developed and maintained. People become engaged in shared self-determination activities through various levels of advocacy, by attention to common values, and because they want to be involved in useful projects. Collective self-determination can be strengthened through educational approaches including psychiatric rehabilitation technology and consumer/survivor programs, such as the exemplary Leadership Academy and Mental Health Recovery Education and WRAP. As leaders learn and grow, so can their followers.

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**UIC NRTC 2003 NATIONAL  
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**DESCRIPTION OF LEAD AUTHORS**

## The UIC NRTC National Self-Determination and Psychiatric Disability Invitational Conference

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**UIC NRTC 2003 NATIONAL  
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**UIC NRTC SELF-DETERMINATION  
BACKGROUND MATERIALS**

# Self-Determination Among Mental Health Consumers/Survivors: Using Lessons from the Past to Guide the Future

By Judith A. Cook, Ph.D. and Jessica A. Jonikas, M.A., the University of Illinois at Chicago National Research and Training Center on Psychiatric Disability

## **Abstract**

It is well known that people with psychiatric disabilities lack self-determination in their lives. A number of studies have demonstrated the high rates of poverty experienced by many of these individuals, leading them to confront a variety of barriers to a higher quality of life. Moreover, concepts of self-determination and client control have not yet proliferated in the public mental health system. In spite of this, consumers/survivors have organized to demand their civil rights and full inclusion in making decisions regarding their own treatment. This article traces the history of self-determination for citizens with psychiatric disabilities, describes major barriers to self-determination, presents several theories of self-determination with potential relevance for mental health consumers/survivors, and offers ways in which self-determination and consumer control might be achieved both within and outside of service systems.

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## **Introduction**

Broadly defined, self-determination refers to the right of individuals to have full power over their own lives. It encompasses concepts that are central to existence in a democratic society, including freedom of choice, civil rights, independence, and self-direction. A more contemporary definition of self-determination reflects its operation at both individual and collective levels, embracing the notion that although all citizens have the right to control their own lives, they exist within communities (defined as families, neighborhoods, cities, states/regions, and countries), in which their decisions affect others and others' decisions affect them (Falck, 1988; Pierce, 2001).

At the beginning of the twenty-first century, low levels of self-determination among people with psychiatric disabilities have been well-documented. Many individuals with this disability live in conditions of extreme poverty and cope with a host of unmet needs. This significantly hinders their ability to have maximal independence and to make meaningful decisions regarding their own lives (del Vecchio, Fricks et al., 2000). Often untreated and unsupported, they experience higher than average levels of unemployment, homelessness, incarceration, chronic medical illness, and social isolation (U.S. Department of Education, 2000). Moreover, concepts of self-determination have not yet proliferated in the mental health system, and consumers'/survivors' perspectives on the issue have not been widely acknowledged. In general, the history of self-determination for people with psychiatric disabilities has been fraught with barriers and challenges. At the same time, or perhaps as a result,

consumers/survivors themselves have organized to demand basic freedoms and rights for themselves and their peers. This article briefly explores this history, addresses ongoing barriers to self-determination, highlights several contemporary theories of self-determination, and presents some ways in which the past may be used to guide the future for citizens labeled with this disability.

### **Self-Determination and the Consumer/Survivor Empowerment Movement**

The earliest advocacy efforts for people with psychiatric labels took the form of personal accounts and written appeals of individuals involuntarily committed to mental hospitals in the late 19<sup>th</sup> and early 20<sup>th</sup> centuries, including Elizabeth Packard, Elizabeth Stone, and Clifford Beers (Chamberlin, 1990). In the 1940s, a group of former state psychiatric hospital patients, called We Are Not Alone, began meeting on the steps of the New York Public library to offer mutual support and friendship. This evolved into the first psychosocial rehabilitation program in the United States (Goertzel, Beard et al., 1960). The mental patients' liberation movement began in the early 1970s with the formation of groups such as the Insane Liberation Front in Portland, Oregon, the Mental Patients' Liberation Project in New York City, the Mental Patients' Liberation Front in Boston, and the Network Against Psychiatric Assault in San Francisco (Chamberlin, 1990). This movement, albeit largely fragmented, strongly advocated for ex-patients' self-determination, asserting that using a medical model to frame intense emotional distress tends to generate dependence and internalized oppression among recipients, compounded by external oppression from society (Unzicker, 1999). The movement's growth was largely aided by the publication, *Madness Network News* as well as the

annual Conference on Human Rights and Psychiatric Oppression, both of which discontinued in the mid-1980s (Chamberlin, 1990).

Additionally, as Chamberlin (1990) detailed, key to the development of the movement was its inclusion – by its own demand – in a series of conferences organized by the federal government's Community Support Program in the late 1970s. During these conferences, consumers/survivors began to advocate for the value of peer-controlled options in community-based systems. Although peer counseling is a central feature of the independent living movement and was even a mandated service in the Rehabilitation, Comprehensive Services and Developmental Disabilities Act of 1978 (Public Law No. 96-602), peer support and self-help did not emerge as a major policy issue for the mental health community until the 1980s and 1990s (Chamberlin, 1995). This was mostly due to the fact that groups without professional supervision or involvement were resoundingly rejected by many clinicians who felt that their clients were too unstable to assist each other without oversight from nondisabled professionals (Ahern & Fisher, 1999) or that self-help would undermine professional care (Kaufmann, Freund et al., 1989). Therefore, advocacy for increased acceptance of self-help and consumer-delivered services among policy makers and mental health/rehabilitation professionals became a central feature of the consumer/survivor movement (Van Tosh, Finkle et al., 1993).

The past two decades also have seen development and popularization of the notion of "recovery" from mental illness. Recovery in this context refers to a process by



which one re-envision and rebuilds one's life following the onset of severe psychiatric symptoms and impairments (Anthony, 1993). The emphasis of this framework is not so much on "curing" or eliminating symptoms and impairments altogether, but instead on learning to cope with them in a way that allows the individual dignity, maximal self-determination, and the highest level of role functioning possible. It is a process whereby people "experience themselves as recovering a new sense of self and of purpose within and beyond the limits of the disability" (Deegan, 1988). As one consumer/survivor put it, ". . . ultimately, patient empowerment is a matter of self-determination; it occurs when a patient freely chooses his or her own path to recovery and well-being. It is the job of mental health services to provide an environment of personal respect, material support, and social justice that encourages the individual patient in this process" (as cited in Ralph, 2000).

As these trends demonstrate, concepts of self-determination and self-direction certainly are not new to individuals who are labeled with psychiatric disabilities. Nonetheless, people with psychiatric disabilities are relative latecomers to civil and disability rights activism (Braddock, 1992; Chamberlin & Powers, 1999). To some extent, this is because for most of the 20th century large numbers of these individuals spent significant proportions of their lives residing in state institutions. This history clouds the present, as society is still ambivalent about whether people with psychiatric disabilities are capable of knowing what is best for themselves and making informed choices. Further, even though the disability and independent living movements strove to change perceptions and societal expectations of people with disabilities from the

1970s to the 1990s (Wehmeyer, 1999), by and large, people with psychiatric disabilities were left out of these movements. This neglect was fostered by the stigmatized views that individuals with psychiatric disorders were violent, volatile, and unable to meaningfully participate in empowerment movements (National Council on Disability (NCD), 2000). Many people with this disability themselves internalized these views as well, feeling either inadequate and unable to trust in their own capacity to direct their lives (Cohan, 1999), or that to identify as an ex-patient would translate into a loss of status and basic rights (Campbell & Schraiber, 1989; Chamberlin, 1990).

Since their deinstitutionalization from public hospitals beginning in the 1950s and 1960s (Gronfein, 1985a; 1985b), people with psychiatric labels have been living in the community for long periods, making sustained social and political participation possible (Cook & Wright, 1995). Consumers/survivors have organized politically and focused on presenting a united front while allowing for diversity and multiple viewpoints in their movement. Given the frequent curtailment of their civil rights, a sensitivity to oppression and a strong desire not to oppress or exclude others characterizes their interactions with others. Along with this comes a tendency to challenge "accepted realities," resisting the status quo and calling for alternatives to standard treatment, some of which make others uncomfortable and challenge "societal power brokers," such as those in the medical and legal professions. Given that consumers/survivors value their unique perspectives on reality, they are unwilling to "homogenize" or exclude certain groups of people in order to gain power (Unzicker, 1999). Additionally, in recent years they have

been actively involved in the passage of several key pieces of legislation that can pave the way for increased self-determination for people with psychiatric disabilities. These include the 1990 Individuals with Disabilities Education Act (IDEA), the 1990 Americans with Disabilities Act (ADA), and the 1999 Ticket to Work and Work Incentives Improvement Act (TWWIIA). These laws mandate a free, appropriate public education to youth with disabilities, reasonable accommodations in employment and public transportation, and removal of work disincentives for people with disabilities seeking return to work, and set the stage for major policy changes that could enhance mental health consumer/survivor self-determination in coming decades.

### **Barriers to Self-Determination for People with Psychiatric Disabilities**

In spite of these efforts to organize and effect policy changes, individuals with psychiatric disabilities have not experienced the levels of self-determination achieved by many other disability groups. Their lives in unwelcoming or unsafe neighborhoods often are difficult, stressful, and unrewarding to the extent that some have suggested that their lifestyles are as disabling as their mental illnesses (Segal & VanderVoort, 1993). Many people believe that these individuals are not as deserving of housing assistance and support as other groups (Center for Mental Health Services, 1998). Because of this, sizable numbers of individuals with psychiatric disabilities are homeless or live in unstable housing (Rosenfield, 1991), and some must reside with parents well into adulthood, resulting in stress and strain on both parties (Cook, Hoffschmidt et al., 1992). These barriers to true self-reliance are played out both at the societal level and in the public mental health system.

Societal Treatment of People with Psychiatric Disabilities. As the hearings conducted by the National Council on Disability (2000) so painfully demonstrated, people with psychiatric disabilities are routinely deprived of their rights in a way no other disability group has been. Indeed, as the report from these hearings documented, people with psychiatric disabilities are the only Americans who can have their freedom taken away and be institutionalized or incarcerated without being convicted of a crime. This widespread discrimination arises because of pervasive misconceptions about the dangerousness of people with psychiatric disorders, resulting in these individuals being deprived of their civil rights in the name of treatment and public safety (Campbell & Schraiber, 1989; Rogers & Centifanti, 1991; Rosenson & Kasten, 1991; Szasz, 1982). As one author put it, "Special laws predicated on what an individual *might do* rather than what a person *has done* are an absolute violation of the most basic of our rights as citizens" (Cohan, 1999). Thus, a strong force of social control of individuals with psychiatric labels is the discrimination and fear they experience, leading them to become "in a thousand little ways more cautious, less expressive, blander, less alive" (Unzicker, 1999).

Moreover, people with psychiatric disabilities often are not perceived as "legitimately" disabled by large segments of society, but instead as malingerers or complainers. Their expressions of their discontent and insistence that their civil rights be protected are viewed by some as evidence of their very insanity. To a large extent, this is due to the well-documented episodic nature of many severe disorders, making it

difficult for lay people to believe that individuals can decompensate and recover rapidly, and enhancing perceptions that they are "faking" their problems. On top of this, individuals with psychiatric disorders continue to be objects of socially-acceptable humor, scorn, and humiliation. It is still acceptable, even at a time when Americans are being called upon to end discrimination against citizens with psychiatric disorders (United States Department of Health and Human Services, 1999) and in an atmosphere of political correctness in our society at large, to mock people with psychiatric problems and their symptoms and to use stigmatizing language. Examples of this type of discrimination are prevalent in the media, and include joking about, imitating, and making light of symptoms and behaviors that are painful and humiliating for those who experience them (Weinerth, 1993). Institutionalized discrimination against people with mental illness is one of the last socially-acceptable, government-sanctioned threats to the rights of a large class of citizens, and makes the realization of self-determination a tenuous and challenging process for many of them (Cook, 2000).

Mental Health Treatment and Rehabilitation. Prejudice and violence against, and maltreatment of, people with mental disabilities extend beyond civil rights to that which is done in the name of treatment (NCD, 2000). Every day, individuals with this disability are expected to trade their freedom in order to receive in-patient treatment, and to submit to medical treatments against their will. This is increasingly occurring in community-based settings as well (Steadman et al., 2001), as evidenced by the recent passage of "Kendra's Law" in the state of New York (New York State Office of Mental Health Initiatives, n.d.) and a lessening of the severity of commitment criteria nationwide

(International Association of Psychosocial Rehabilitation (IAPSRs) 2000). Additionally, for some consumers, psychiatric treatment includes coercion, which involves emotional intimidation, threats, and bullying, as well as forced restraint, forced seclusion, and chemical restraint in in-patient settings (IAPSRs, 2000; NCD, 2000). Many have argued that such "treatment" victimizes or re-victimizes individuals by perpetuating illness and internalized oppression rather than enhancing health and well-being (Jennings, 1994). Others have noted that such coercive treatment prevents many people from seeking formal assistance again, and that the very notion of self-determination within a system that includes forced treatment and loss of basic rights and freedoms is untenable (Fisher & Ahern, 1999; Unzicker, 1999). In general, individuals with mental health problems have experienced minimal self-determination, given society's failure to provide them with adequate, recovery-oriented services or choices for how to use available services (Ahern & Fisher, 1999; Lamb, 1994), with only one in four adults with disabling psychiatric disorders receiving any mental health treatment (Manderscheid, Henderson, et al., 1998). For those who do seek help, services often fall far short of those considered even minimally adequate for clinical care, rehabilitation, and recovery (Lehman, Steinwachs et al., 1998).

Because of these threats to basic rights and the lack of adequate, recovery-oriented services, mental health advocates have come to define *self-determination* as clients' rights to be free from all involuntary treatment; to direct their own services; to be involved in all decisions concerning their health and well-being; and to have meaningful

leadership roles in the design, delivery, and evaluation of services and supports (Aiken & Catalano, 1994; Davis & Aroskar 1983; King 1991; National Alliance for Self-Determination, 1999). It is also critical that they be permitted the liberty to determine their own actions according to personally-developed goals (Beauchamp & Childress, 1983). Unfortunately, these concepts have not yet proliferated in the mental health system, and consumers'/survivors' perspectives on the issue have not been widely acknowledged. For example, many rehabilitation-oriented models of service delivery such as Clubhouses, Fairweather Lodges, and Assertive Community Treatment programs, cite assisting clients in exercising self-determination as their central mission. However, some advocates have called into question the extent to which self-determination occurs in most established community treatment models (Fisher & Ahern, 1999; Unzicker, 1999), particularly for people of color (Neighbors, Elliot et al., 1990; Snowden & Lieberman, 1994). Too often, self-determination is viewed as a *privilege* to be earned rather than as a *right* (Chamberlin & Powers, 1999). In these settings, service consumers often are "rewarded" for treatment compliance by being given "opportunities" for self-determination (Unzicker, 1999).

Additionally, the introduction of managed care into public mental health systems also has been associated with reduced levels of client choice and consumer control of their own treatment (Head & Nerney, 1999). Specifically, as Nerney and Shumway (1996) noted, certain elements of managed care directly contradict principles of self-determination for people with disabilities. First, managed care's restriction of providers to only those in established networks limits consumer choice regarding where and from

whom they receive services. Second, utilization review and prior authorization of services by a centralized management authority is in direct opposition to putting management of personal life goals directly in the hands of consumers and their supporters. Nerney and Shumway argued that only cost containment is consonant with self-determination's foundation of starting with natural supports and using professionals only when necessary. Clearly, the reliance of large numbers of people with psychiatric disorders on the public mental health system for their care has created conditions that may be largely hostile to enhancement of self-determination.

The byzantine disability income policies faced by Social Security Disability Income (SSDI) and Supplemental Security Income (SSI) recipients are also hindering self-determination for people with psychiatric disabilities. Because of their reliance on disability income and associated health care coverage for health and mental health services (Ho, Andreasen et al., 1997), consumers are subject to unpredictable, often capricious changes in disability policies and administrative procedures. For example, in the 1980s, thousands of persons with psychiatric disabilities were removed abruptly from the SSI rolls, cutting them off from their major means of financial assistance and health care (Anthony & Jansen, 1984). With so little control over their own financial situations and futures, many people with psychiatric disabilities are forced to live in poverty (Cohen, 1993) and, even when they are employed, exist at the level of the "working poor" (Baron, 2000; Kouzis & Eaton, 1994).

Other authors have identified barriers to self-determination in service settings



that include ongoing debates about whether people with psychiatric disabilities are consistently competent to make their own decisions (Valimaki & Leino-Kilpi, 1998); lack of concrete models and formal education about fostering self-determination among clients (Rothman, Smith et al., 1996); and programmatic budget cuts, overwhelming caseloads, paternalistic treatment models, and lack of self-advocacy training for consumers (Tower, 1994).

Mental Health Provider Education. There is widespread agreement that professional education and training programs in the core disciplines of psychology, social work, psychiatric nursing, and psychiatry have failed to prepare students adequately to serve persons with psychiatric disabilities (Anthony, Cohen et al., 1988). For example, university training curricula and textbooks in psychology tend to emphasize drug and hospital treatment of individuals with psychiatric disability over community-based rehabilitative strategies, peer support, and self-help (Halter, Bond, DeGraaf-Kaser., 1992). Rarer still is training that encourages future providers to view clients as self-determining agents of their own change, capable of making informed choices about their treatment and recovery (Cook, Jonikas et al., 1995). Even fields such as social work, which teaches students that client self-determination is desirable (Tower, 1994), fail to offer adequate guidelines or clinical strategies to encourage client self-determination in practice settings (Rothman et al., 1996). Therefore, as a result of their antiquated or inadequate training, many of the providers with whom people with psychiatric disabilities come into contact are unknowledgeable about or unsupportive of their clients' rights to self-determination and freedom of choice, including the choice to

refuse treatment entirely.

Clearly, people with psychiatric disabilities continue to face many barriers to true self-reliance and basic guarantees of their civil rights. They also confront numerous challenges to their desires to be in control of their own mental health treatment, to have full access to recovery-oriented services, and/or to forego professionally-based services for those operated by their peers.

### **Contemporary Theories of Self-Determination**

Several contemporary theories of self-determination have the potential to help people with psychiatric disabilities overcome these barriers to achieving full control of their own lives, both at societal and system levels.

Social Self-Determination. As a response to demands for self-determination for service recipients, some authors have noted that the very concept of self-determination rests on a problematic foundation of total individualism, implying that individuals, or even groups of individuals, can be removed from their complex societal contexts (Falck, 1988; Pierce, 2001; Schwartz, 2000). To overcome this problem, these authors proposed the concept of **social self-determination**, noting that networks of clients, families, providers, agencies, systems, and communities are made up of social beings, inextricably interlinked. Although the integrity and autonomy of each human being is essential, this theory of self-determination purports that there are dangers in defining personal freedom solely as the ability to make decisions that maximize personal benefit. Such a framework supports the questionable notion that a person is a closed, bounded

self, rather than a person who contributes to others and is contributed to by others (Falck, 1988). In fact, freedom is a social benefit (rather than an individual one), because everyone has to live with their own decisions and their consequences for others, and vice versa. Under this framework, all decisions and actions on the part of people with psychiatric disabilities, and those in their social networks, are formed by and have consequences not just for themselves but for other human beings, a social connectedness which could strengthen theories and models of self-determination in psychiatric disability. Social or shared self-determination also recognizes the *interdependence* valued by so many diverse cultures, rather than the complete independence prized in Western society.

From Recovering to Thriving. Another relevant theoretical notion, borrowed from the field of social psychology, is that of *thriving* (Carver, 1998). Thriving is a process in which individuals' experiences of dealing with adverse life events such as illness, warfare, or trauma lead them to become better off than they were before. This is illustrated in Figure 1, which shows four potential trajectories following the swift drop in level of functioning that accompanies the occurrence of major adversity in an individual's life. If, after experiencing adversity, the individual's level of functioning declines even more over time, he or she is *succumbing*. If functioning increases slightly but not to prior levels, the individual is said to experience *survival with impairment*. Those whose functioning improves over time and reach its pre-trauma level experience *recovery* and display *resilience*. However, those whose functioning improves to pre-trauma levels *and then surpasses prior quality of life* are said to be *thriving*. A large

body of research confirms that individuals can thrive after coping with an array of adversities, such as warfare and torture (Karakashian, 1998), physical and sexual abuse (Saakvitne, Tennen et al., 1998), and life-threatening illness such as cancer (Snodgrass, 1998). Thus, a central question for the consumer/survivor movement is whether and how self-determination can help to ensure a recovery process that includes thriving.

A New Paradigm of Disability. Complementing these new conceptualizations is the "***New Paradigm***" of disability in the field of rehabilitation (DeJong & O'Day, as cited in National Institute on Disability and Rehabilitation Research, 1998). This paradigm views disability as an interaction between characteristics of an individual and features of his or her cultural, social, natural, and built environments (Hahn, 1999). In this framework, disability does not lie within the person but in the interface between an individual's characteristics, such as their functional status or impairments or personal or social qualities, and the features of the environment in which they operate. Whereas the old paradigm views a person with a disability as someone who cannot function because of an impairment, the new paradigm views this person as someone who needs an accommodation in order to function. Moreover, it acknowledges that people are entitled to accommodations as a civil right under the ADA.

The new paradigm shifts the focus away from solely being on the individual to equally encompassing the environment. It highlights how the environments of people with psychiatric disabilities often are socially inaccessible, economically

unaccommodating, legally exclusionary, and emotionally unsupportive. It also directs the search for solutions and remedies away from "fixing" individuals or correcting their deficits to removing barriers and creating access through accommodation and promotion of wellness and well-being. Concomitantly, the source of the intervention is no longer mental health professionals and clinical/rehabilitation service providers but peers, mainstream providers, and consumer advocacy and information services. Most importantly, in the new paradigm the role of the person with a psychiatric disability shifts from being an object of intervention or a patient to one of a customer, empowered peer, and decision-maker.

All of these contemporary theories emphasize the ways in which self-determination operates at both individual and environmental levels. They put forth social connectedness, thriving, and an accommodating environment as key determinants of self-determination for all people, including those with disabilities. As such, they have great potential for guiding the ways in which self-determination can be fostered for people labeled with psychiatric disabilities at the individual, societal, and mental health system levels.

### **Looking to the Future: Where do We Go from Here?**

Given the struggle that people with psychiatric disabilities have endured in hopes of achieving self-determination and personal/social liberty, there are a number of avenues to explore to ensure a better future for these individuals. As a first step, Nelis and Pederson (1999) noted that many more people with disabilities must be educated

about what self-advocacy and self-determination mean for them and how they might realize these goals in their own lives. The fact that self-determination is a life-long endeavor for most people should be emphasized, thus taking into consideration the steps forward and backward that all people experience in their journey toward self-actualization and a freely-lived existence (Rogers, 1995). As more individuals with psychiatric disabilities embrace their own capabilities and rights, they will be in a better position to demand respect and their inclusion in all decisions that affect their lives. This type of “consciousness raising” also can be effective in helping more consumers and psychiatric survivors to organize and advocate for full inclusion, basic civil rights and freedoms, and accurate portrayals in the media and larger culture (Oaks, 2001). When addressing these issues, it is critical to place an emphasis on cross-disability and cross-liberation efforts (Chamberlin, 2001) because many people with disabilities and those who are otherwise disenfranchised share many common experiences that once overcome can increase both recovery and thriving.

It is necessary that we gain a better understanding of what self-determination actually means to people with psychiatric disabilities, their families, and other stakeholders. It is also important to expand exploration of how to foster increased control over one’s life while taking into consideration social connectedness. Certainly, more information is needed about the barriers that preclude realization of consumer choice and self-determination, and how the many people and systems with whom consumers/survivors come into contact can respect their individual rights. In developing

such theories and practice models, it is crucial to draw upon concepts of self-determination that embrace not only individuals and systems, but the larger culture as well. This type of theory building and model development is one of the major emphases of the University of Illinois at Chicago's National Research and Training Center's on Psychiatric Disability.

Within the mental health system, a number of strategies could begin to help consumers to foster self-determination and true choice. First and foremost, many consumers/survivors are advocating for the end of forced treatment at all levels (National Alliance for Self-Determination, 1999; NCD, 2000). In order for this to occur, more consumers and psychiatric survivors must assume leadership roles in local, state, and national policymaking, to ensure that the issues that they are most concerned about are brought to the fore (Imparato, 1999). In order to increase choice and eliminate coercion, the widespread introduction of *psychiatric advance directives* (PADs) and other mechanisms that allow people to voluntarily determine what sorts of treatments and supports they most desire is extremely important. To achieve this goal, more people with psychiatric disabilities, their supporters, and those in the legal system must be educated about the value and logistics of PAD creation and useage.

Encouragement and support for the development of self-help groups and other peer-run options also could foster self-determination for people with psychiatric disorders. In order to avoid co-optation, these groups must be led by people who have experienced psychiatric disability and the many individual and societal difficulties

accompanied by this label (Chamberlin, 1990). Formal providers and family members should be educated about the value of self-help and the ways in which to link clients and relatives to such options.

In terms of service receipt, it is helpful to draw upon the tripartite definition of self-determination for people with disabilities suggested by Nerney and Shumway (1996). Echoing other authors, they argue that increasing consumer choice and desirable service options is central to true self-determination in service systems. Here, too, using PADs and other such strategies is paramount, as is the development of recovery-oriented, voluntary, community-based services and supports throughout the country. In addition, putting management of personal life goals directly into the hands of consumers and their supporters is a second dimension that fosters self-determination. Finally, using natural supports and avoiding professional intervention unless absolutely necessary rounds out their notion. Thus, Nerney and Shumway argued that a central question of how self-determination can be enhanced in treatment settings is how people with disabilities can "fundamentally reform both financing mechanisms and basic structural aspects of the current service delivery system."

Drawing upon the new paradigm of disability, the mental health system at large would benefit from shifting its current focus on "individuals who are limited by their impairments or conditions" to "individuals who require accommodations to perform functions required to carry out life activities" (DeJong & O'Day, as cited in National Institute on Disability and Rehabilitation Research, 1998, p.7). In this way, service



recipients would be viewed as having a ***right*** to voluntary, recovery-oriented services and supports, as well as personal assistants, job and education coaches, and full access to information technology that would allow them to learn about and advocate for their rights while offering and receiving peer support (Caras, 2001). The latter point is crucial for enabling individuals to develop effective strategies for applying self-determination theories and models to their everyday lives. The gap between knowledge development and knowledge application has been well-documented (Zeren, Taylor, Leff, et al., 1999), as have methods for overcoming this problem through ongoing and innovative dissemination and self-advocacy training strategies, especially those involving use of advanced technology (National Center for Dissemination of Disability Research, 2000).

Although the journey toward full self-reliance and consumer control has been arduous for people with psychiatric disabilities, advancements have been made in increasing their voice and visibility of issues that are most important to them at system and societal levels. At the beginning of the 21<sup>st</sup> century, there is more hope than at any other time in history that people with this disability will one day achieve maximal independence and full participation in community life.

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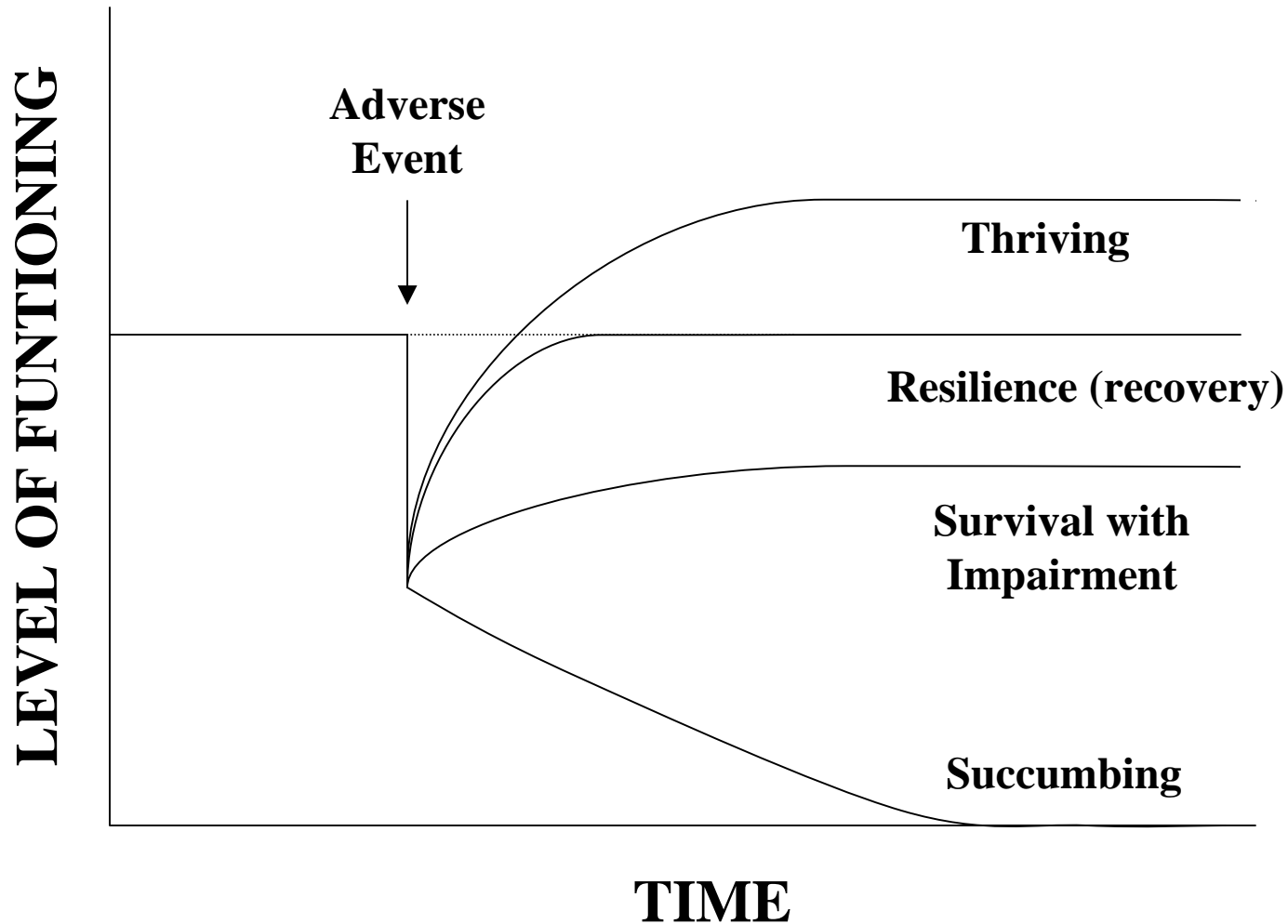
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**Figure 1. Potential responses to trauma**

(Note. From: "Issues, models, and linkage," by C.A. Carver, 1998, Journal of Social Issues, 54(2), p. 246. Copyright 1998 by Blackwell Science Ltd. Reprinted with permission.)

## **SELF-DETERMINATION FRAMEWORK FOR PEOPLE WITH PSYCHIATRIC DISABILITIES<sup>†</sup>**

### **Brief Definition**

Self-determination refers to the right of individuals to have full power over their own lives, regardless of presence of illness or disability. It encompasses concepts such as free will, civil and human rights, freedom of choice, independence, personal agency, self-direction, and individual responsibility. Self-determination in the mental health system refers to individuals' rights to direct their own services, to make the decisions concerning their health and well-being (with help from others of their choice, if desired), to be free from involuntary treatment, and to have meaningful leadership roles in the design, delivery, and evaluation of services and supports.

### **Taxonomy**

Given the brief definition, a taxonomy or classification of self-determination includes the following elements, categorized into three, interrelated levels: 1) individual or internal self-determination/recovery; 2) mental health programming, services, and supports that foster self-determination; and 3) collective, social, or shared self-determination.

#### **Level One: Individual or Internal Self-Determination/Recovery**

This level highlights the importance of individual empowerment to fulfill one's own inner capacity for self-determination and recovery. Self-determination is achieved at this level when people have maximal independence and educational opportunities to make meaningful decisions about their own lives, control their own money, and live and work where they choose. This level focuses on capacities such as:

- Personal resolve and belief in oneself and one's ability to be a fully self-determining individual
- Development and achievement of personally meaningful life goals
- Learning and demonstrating leadership abilities
- Self-management of disability that promotes self-respect and self-advocacy
- Achievement of economic independence and prosperity, through means of one's own choice that serve to enhance personal values and needs (via such things as training for decent jobs at decent pay, running one's own business, or becoming a home owner)
- The ability to overcome internalized stigma/discrimination, to demand the best treatment or treatment alternatives possible, to advocate for one's rights, and to live in communities of choice, free from fear, loneliness, and impoverished conditions, in order to achieve life dreams

#### **Level Two: Mental Health Services, Supports, and Policies that Foster Self-Determination**

This level pertains to innovations within public and private service systems, as well as among informal caregivers and peers, that foster self-determination. These systems include those that address mental medical and mental health treatment (with the help of others of their choice, if desired), are free from involuntary treatment, and have leadership roles in the design, delivery, and evaluation of services, and physical health, vocational rehabilitation/training, housing, income support, and education. At

this level, self-determination is achieved when individuals make decisions regarding their own supports, and policies. This level focuses on promoting practices that foster self-determination, including:

- Recovery-oriented services/supports that respect client choice of service providers and treatment options
- The right to confidentiality and access to all records/documents about one's self or treatment
- Services/supports that honor clients' cultural experiences, norms, beliefs, and values, as well as their gender, age, religion, and sexual orientation
- Alternatives to traditional treatment, including those that are led by individuals who seek, use, or have used mental health services (including self-help and peer support)
- Traditional mental health programs staffed by people who seek, use, or have used services
- Housing alternatives and choices that are independent of treatment and the mental health system and that respect personal wishes and choice of supports/assistance, if desired
- Employing strategies to prevent coercive or forced treatment
- Psychiatric advance directives and other mechanisms for voluntarily determining acceptable treatments and supports
- Learning/resource centers (with access to print and audio/visual materials, as well as information technologies) to help people become experts on their own needs and lives
- Meaningful involvement of people with psychiatric disabilities from various backgrounds in local, state, and national policymaking to ensure focus on issues of most concern to them
- Systems change and community organizing activities to ensure civil and human rights in service systems and society at large

### **Level Three: Collective, Social, or Shared Self-Determination**

This level focuses on the political, economic, cultural, and social context in which people live, work, participate in community activities, raise families, socialize, and otherwise relate to each other casually or intimately, individually or in groups. At this level, self-determination is achieved when individuals are full participants in community life, and are empowered to organize for social justice for themselves and their peers. It acknowledges that no one is free until all are free. It focuses on promoting principles, values, and actions that advance global self determination, including:

- The importance of social connectedness in achieving self-determination (i.e., we all exist in relation to others – our decisions have consequences for ourselves and others)
- Collective, grassroots, cross-disability organizing to build alliances, increase strength and power, and unite in common concerns to take action. Such coalitions work to ensure basic civil and human rights, to fight societal discrimination and oppression (including based on disability, race, ethnicity, culture, gender, age, religion, and sexual orientation), and to overcome service and societal barriers
- The value of networking and community/collective organizing (in person, in groups, or via information and communication technologies) to share history, strength, resources, and hope in order to combat isolation, discrimination, and other life challenges
- Mutual respect for differences in beliefs, viewpoints, lifestyles, needs, and morals, in order for self-determination to be truly realized