Self-Determination
for People with Psychiatric Disabilities:
An Annotated Bibliography of Resources

Compiled by Staff of the University of Illinois at Chicago, National Research and Training Center on Psychiatric Disability and its Self-Determination Knowledge Development Workgroup

<u>Staff and Workgroup members</u>:

Larry Belcher
Judi Chamberlin
Judith Cook
Kathleen Furlong-Norman
Barbara Granger
Ramiro Guevara
Tamar Heller
Marty Hines
Leah Holmes-Bonilla

Catherine Huynh
Jessica Jonikas
Alexandra Laris
David Oaks
Laurie Powers
Joseph Rogers
Andrea Schmook
Suzanne Vogel-Scibilia
Amanda Taylor

Suggested citation: UIC National Research & Training Center on Psychiatric Disability and the Self-Determination Knowledge Development Workgroup. (2002). *Self-Determination for people with psychiatric disabilities: An annotated bibliography of resources.* Chicago, IL: Author.

History, Definitions, and Principles of <u>Self-Determination & Recovery</u>

Alliance for Self-Determination, Center on Self-Determination, Oregon Health Sciences University. (1999). *National Leadership Summit on Self-Determination and Consumer-Direction and Control: Invited papers.* **Portland, OR: Author.**

This monograph contains the commissioned papers for the National Leadership Summit on Self-Determination and Consumer-Direction and Control, held in Bethesda, Maryland, October 21-23, 1999. The Summit was sponsored by the Alliance for Self-Determination. The invited papers focus on **four major topics**: 1) What is the history of self-determination and consumer-direction, and how is it defined across disability groups; 2) What can individuals, families, and communities do to enhance consumer-direction and self-determination; 3) What regulatory and policy changes are needed to advance consumer-direction and control; and 4) How can we ensure that people with disabilities lead self-determination and consumer-direction initiatives?

The first collection of papers focuses on the first of these four questions. The common themes include civil rights, personal freedom, and choice and control over one's life. Emphases are on freedom from forced treatment, institutionalization, and segregated schooling; living and working where one chooses; self-advocacy and making one's own decisions; controlling one's money; and choosing and directing services and supports. A call is made for a unified platform between those with physical and psychiatric disabilities. Common barriers to self-determination addressed include: 1) defining disability as a medical problem versus a sociopolitical issue; 2) lack of generalization and cross-disability partnerships; 3) restricted access to leadership roles by people with disabilities; 4) societal attitudes that view people with disabilities or those in need of support as dysfunctional and needing to be fixed; and 5) general support for the idea of consumer-direction that doesn't get translated into actual policies and practices to promote/ensure self-determination.

The second collection of papers focuses on the second of the four major questions. Common themes include the need: for people with disabilities and their families to determine their own needs, preferences, etc. before they can exercise choice; to recognize families as a primary mechanism to encourage self-determination; to acknowledge peer support as primary to the "culture" of self-determination; to accommodate cultural diversity; to be highly individualized; for skills training and services management equipping people with disabilities with tools they need for self-management; inclusion in integrated settings; communities to be accessible (broadly defined) to people with disabilities; and more affordable housing, transportation, and meaningful work. Some of the barriers mentioned include that people with the most severe cognitive disabilities often are left out of the self-determination movement; that

these individuals may require lifelong and extensive support to help them exercise self-determination; that there is often tension between individuals' preferences for autonomy and independence and families' desire for safety and protection for them; and the culturally-transmitted stigma attached to having a psychiatric disability.

The third collection of papers focuses on the third of the four major questions. Common themes include that: 1) policies and regulations do not support choice and self-determination; 2) there is a lack of understanding and support for the long-term and quality of life needs and preferences of people with disabilities of all ages; and 3) input from people with disabilities is lacking at all levels of policy-making.

The final collection of papers focuses on the fourth of the four major questions. Common themes include: 1) the negative social attitudes toward persons with disabilities, which hinder self-determination; 2) client-direction and control can be somewhat undermined or contradicted when they are conveyed by persons without disabilities; 3) the lack of leadership roles for people with disabilities reinforces an image of dependency; 4) the tendency for nondisabled persons to remain in charge of service systems can undermine self-determination; 5) transportation barriers and failure to accommodate differences in functioning can impede self-determination; and 6) poverty, educational disadvantage, job discrimination, and internalized oppression all can impede self-determination.

Chamberlin, J. (1990). The ex-patients' movement: Where we've been and where we're going. *The Journal of Mind and Behavior, 11*(3), 323-336. Http://www.mhcan.org/Judi-c.html

Even though a complete history of the "mental patients' liberation" movement has yet to be written, in this article the author describes main developments in the movement. Specifically, she describes a number of issues, such as: the guiding principles of the movement, which includes the exclusion of non-patients and consciousness-raising; historical development of the movement, including the beginnings of the Madness Network News, the Conference on Human Rights and Psychiatric Oppression, and the activities of several other groups; self-help and empowerment principles put into action through the movement; advocacy which goes "beyond the individual" and is guided by the principle that all laws and practices which induce discrimination must change so that diagnoses do not affect a person's rights and responsibilities; and the current (1990) status of the movement.

Contra Costa County Mental Health Recovery Task Force. (2000, April). *The recovery model: A conceptual framework and implementation plan.* Paper distributed at the Adult System of Care Conference, Santa Clara, CA.

This short concept paper presents this task force's definitions and models of recovery, which arose from incorporating recent literature and the experiences of people with

psychiatric disabilities, practitioners, and administrators across the country. They highlight the concept of recovery, the distinguishing features of the recovery model (i.e., basic assumptions, perspective shifts, new roles, support systems, and social change), and implementation tasks of their task force. The three appendices cover the benefits of the recovery model training for individuals with psychiatric disabilities, health care providers, and the development of wellness recovery centers.

Cook, J.A., & Jonikas, J.A. (in press). Self-determination among mental health consumers/survivors: Using lessons from the past to guide the future. *Journal of Disability Policy Studies.*

This article begins with a brief history of self-determination for people with psychiatric disabilities. It turns to a discussion of major barriers to self-determination, including the societal treatment of people with psychiatric disabilities, lack of approaches to foster self-determination within mental health treatment and rehabilitation systems, and insufficient education about self-determination among providers and other supporters. The authors present several contemporary theories of self-determination and offer ways in which self-determination and client control might be achieved both within and outside of service systems for people with psychiatric disabilities.

Falck, H.S. (1988). *Social work: The membership perspective.* New York: The Springer Publishing Company, Inc.

In this book, the author (a Holocaust survivor) puts forth the position that the old concept of self-determination requires modification to ***social self-determination***. According to his theory, it must be recognized that the client, the provider, the agency, the system, and the community are made up of social beings, inextricably connected. While the author does recognize the importance of celebrating the integrity and autonomy of each human being, he also believes that the very same integrity and autonomy are social products that result from being linked with others (in positive, negative, and ambiguous ways).

Falck (p. 17) describes the limitations that arise when defining the end goal of self-determination as "independence." He states, "... self-determination shows up in social work as an allegedly democratically determined right. But this democracy is minimal because it assumes that self-determination speaks to independence, which is limited only by the extent to which others enjoy the same separate right. Implicit in social work's usual definition of the right to self-determination is a total disregard of the fact that all decisions, self-determined or not, are social in nature and are, therefore, of immediate interest to others."

He also believes (p. 19) that problems arise when we define personal freedom as the ability to make decisions that maximize personal benefit. First of all, he says that this definition supports the incorrect notion that a person is a closed, bounded self, rather

than a person who contributes to others and is contributed to by others. Second, he believes that it incorrectly postulates that freedom is an individual benefit that occurs without reference to others, when in fact, everyone has to live with his/her own decisions **and** their consequences. He says (p. 71-72), "One of the inescapable consequences of using the right to self-determination as the philosophical rationale for decision-making is that one either encourages the client to think only of his/her own interests or to think of him/herself as the sole person who determines what to do and what not to do." Under Falck's "membership perspective," however, decision-making rests on **social self-determination** (i.e., decision-making by the social self). All decision-making must take into account the individual and the meanings the individual's decisions have for other people. No matter what the decision, there are consequences with which not only the decision-maker but others must live.

Interestingly, Falck rejects the term "consumer" of services (first put forth by Maluccio, 1979) and the term "intervention." It's his belief that consumerism addresses only the reactions of "customers" and "intervention" speaks to what social workers "do" to clients. Both of these do not address the mutuality and connectedness of the client and provider. The evaluation of social work services should instead address what clients and providers achieve or fail to achieve **together**.

First International Conference on Self-Determination and Individualized Funding Attendees. (2000, July). *Seattle 2000 Declaration on Self-Determination and Individualized Funding.* Retrieved March 27, 2002, from http://www.bccpd.bc.ca/if/updocs7/declare.html

This document outlines 35 principles of self-determination. It calls on policy makers and providers at all levels to ensure that assistance is made available to support these principles of self-determination. The 35 statements are divided into 5 global areas: Founding Principles; Action Required to Support Self-Determination; Individualized Funding, Guiding Principles; Individualized Funding, Principles for Implementation; and Individualized Funding, Evaluation.

Fleischer, D.Z., & Zames, F. (2001). *The Disability Rights Movement: From charity to confrontation.* Philadelphia: Temple University Press.

The authors based their book on interviews with nearly a hundred activists. Their account provides a history of the struggle for disability rights in the United States. It presents the complexities of change in consciousness and policy as they relate to blindness, deafness, polio, quadriplegia, psychiatric disabilities, developmental disabilities, and other conditions such as cancer, heart disease, and HIV/AIDS. The book recaps the origins of the disability rights movement as early as the 1930s, as well as through the independent living movement in the 1970s, and the disability pride of the 1990s. Like other social movements, this one has taken place in the streets and courts as activists worked to change schools, the workplace, and the legal system. Their

efforts culminated in the passage of the Americans with Disabilities Act in 1990.   A sense emerges that, unlike the experiences of other oppressed groups, anyone can become disabled and face discrimination as a result.

Ingstad, B., & Whyte, S.R. (Eds.). (1995). *Disability and culture*. Berkeley, CA: University of California Press.

The United Nation's International Decade for the Disabled and anthropologists' exploration of the effects of culture on the lives of people living with mental and physical disabilities were the forces that forged this collection of essays of medical anthropology. Rather than examining disability as a medical condition, the collection views disability in terms of a socio-political construction so as to reframe disability in multicultural perspectives. Anthropologists who made contributions to this book conducted research in a wide variety of settings from longhouses in Borneo to communities of Turkish immigrants in Stockholm. Their intent was to look at the significance of these disabilities in light of predetermined, cultural assumptions about humanity and personhood.

Jacobson, N., & Greenley, D. (2001). What is recovery? A conceptual model and explication. *Psychiatric Services, 52*(4), 482-485.

This paper presents a model of recovery that refers to both internal conditions and external conditions. Internal conditions include the presence of hope, healing, empowerment, and connection within the person. External conditions include implementation of the principle of human rights, a positive culture of healing, and recovery-oriented services. The purpose of the model described in this paper is to link abstract concepts of individual recovery with specific strategies that can be utilized by systems, agencies, and individuals.

Kennedy, M., & Lewin, L. (n.d.). *Fact sheet: Summary of self-determination.* Retrieved April 6, 2000, from http://soeweb.syr.edu/thechp/SELF_DETERMINATION.html

This internet fact sheet outlines some basics of self-determination, beginning with a short description of its person-centered and person-directed nature. It briefly describes four principles of self-determination, which are freedom, authority, autonomy, and responsibility, and five values supported by self-determination, which are respect, choice, ownership, support, and opportunity. The sheet ends with a call to action for making changes in the way service providers and funders think about and serve people with disabilities. The writers call for a shift from seeing deficits and limitations to focusing on strengths, rights, person-directed services, individual financial control, and empowerment.

National Council on Disability. (2000). *From privileges to rights: People labeled with psychiatric disabilities speak for themselves.* Washington, DC: Author. Http://www.ncd.gov/newsroom/publications/privileges.html

In November, 1998, the NCD conducted a hearing specifically on the unique perspectives, strengths, and challenges of people with psychiatric disabilities, with the primary participants being those who have been labeled themselves. The testimony was often gripping and painful, pointing to the fact that people with psychiatric disabilities often are systematically and routinely deprived of their rights, and treated as less than full citizens or full human beings. As a result of this hearing, **the NCD developed 10 core recommendations** which are summarized in this report. While these recommendations are too lengthy to include in full here, the following is a summary of what was suggested. First, laws that allow the use of involuntary treatment should be viewed as counter to self-determination. Public policy needs to move in the direction of a completely voluntary, community-based system that safeguards human dignity and autonomy. Second, people with psychiatric disabilities should have a major role in the direction and control of programs and services designed for their benefit. Third, mental health treatment should be about healing, not punishment (phasing out such things as involuntary treatments, restraint/seclusion, and ECT). Fourth, federal research and demonstration resources should place higher priority on the development of culturally appropriate alternatives to the standard medical and biochemical approaches to treatment, which would include self-help and peer support. Fifth, eligibility for services in the community should never be contingent on participation in treatment programs. Sixth, employment, training, and vocational rehabilitation programs must account for a wide range of abilities, skills, knowledge, and experience of people labeled with psychiatric disabilities. Seventh, federal income support programs like SSI and SSDI should provide flexible and work-friendly support options (especially for individuals with episodic or unpredictable disabilities). Eighth, parity laws should define parity only in terms of voluntary treatments and services. Ninth, government civil rights enforcement agencies and publicly-funded advocacy organizations should work more closely and with adequate funding to enforce existing disability laws, such as the ADA, Fair Housing Act, etc. Tenth, federal, state, and local governments must work together to reduce the placement of children and young adults with disabilities (especially those labeled seriously emotionally disturbed) in correctional facilities or other segregated settings.

Nerney, T., Crowley, R.F., & Kappel, B. (1997). *An affirmation of community: A revolution of vision and goals, creating a community to support all people including those with disabilities.* Retrieved April 7, 2000, from http://www.unh.edu/rwj/library/afc.htm

This manuscript was written as a call to action and an illustration of changes needed to become more responsive to people with disabilities in a community. It is divided into seven chapters, each of which outlines a separate dimension of what the authors

describe as an affirmation of community that supports self-determination for people with disabilities. They begin with a series of "simple truths," such as the fact that all communities have as members people with disabilities, and that they are being harmed. They then describe a vision of what could be, describing people with disabilities as vital and integral members of the community that are being supported and are determining their own futures. Next, the authors describe new goals for a new future, which include self-determined personal support, housing for inclusion, elimination of the congregate model, equal access to employment, and universal physical accessibility. Also included is a chapter on principles for action, which are self-determination and control, "whatever it takes" to get things done, choice and voluntary association, contribution, and fiscal conservatism. The authors then go into conditions for success, discussing person-, agency-, and provider-level approaches. Strategies to achieve the goals and honor the principles are outlined, and include the wiser use of funds, the shift of power and influence, the re-orientation of major components of the service system, the development of a culture of accessibility, and keeping the vision in focus. Finally, the authors describe a new way of looking at existing supports.

Pierce, R.D. (2001, October). *Self-determination through the prism of community.* Paper presented at the UIC NRTC Self-Determination Workshop Series, Chicago, IL.
Http://www.psych.uic.edu/UICNRTC/rpierce-sdworkshop.pdf

In this paper, the author describes an alternate definition of self-determination that draws upon the momentous struggle of African Americans and women, who invoked the language and principles of self-determination to end segregation and address conditions of repression. To them, self-determination was a moral and political value that transcended race and class, and a principle that was used to unify communities. The author draws upon these beliefs to show how self-determination is an expression of sovereignty, and can be viewed as both a right and a responsibility to self and others. He describes how self-determination links individual respect with communal health and happiness. He reasons that conditions that affect the individual also affect the community as a whole. The author concludes that all people are interconnected, such that if one people are shackled, then too are all people. In considering concepts of self-determination, Pierce reminds us that none are free until all are free.

Ralph, R.O. (2000). Recovery. *Psychiatric Rehabilitation Skills, 4*(3), 480-517.

This review of the published and unpublished literature (mostly written or compiled by people with psychiatric disabilities) provides definitions of recovery and describes studies demonstrating that people recover and how they recover. **Dimensions of recovery** include: 1) internal factors (within the person her/himself); 2) self-managed care (an extension of internal factors); 3) external factors (interconnectedness with others; supports from professionals, family, and friends); and 4) empowerment (a combination of internal and external factors, where internal strength is combined with

interconnectedness to provide self-help, advocacy, and caring about what happens to self and others).

Among the many interesting and useful definitions of empowerment offered, Clay's (1990) stands out as being useful to efforts to build a definitional framework for self-determination. She discusses "Patient Empowerment" in terms of **personal empowerment, social empowerment, and civil empowerment**. Personal empowerment includes such qualities as self-esteem, confidence, and respect for others, which translate into an inner authority to act as a free and useful person. Social empowerment includes decent affordable housing and meaningful work for decent pay. It also includes the support of friends, family, and services, which foster choice and growth. Civil empowerment includes the assurance of client rights, such as the right to informed consent in treatment, to the least restrictive setting, to information about treatment, to participation in one's own treatment, to assert grievances, and to due process, especially regarding commitment and forced treatment. Clay is quoted as saying, ". . .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."

Ralph, R.O. (2000). *Review of recovery literature: A synthesis of a sample of recovery literature 2000*. Alexandria, VA: National Association of State Mental Health Program Directors (NASMHPD)/National Technical Assistance Center for State Mental Health Planning (NTAC).
Http://www.nasmhpd.org/ntac/reports/ralphrecovweb.pdf

This review focuses on different types of literature on recovery from the perspectives of individuals with psychiatric disabilities, and how it pertains to services and supports. The author begins the booklet with a brief review of the origins of the concept of recovery and diverse definitions of the topic from the writings of people with psychiatric disabilities. She then goes on to describe two types of recovery literature: personal accounts and "how to recover." In terms of the personal accounts literature, she describes four dimensions: internal factors, self-managed care, external factors, and empowerment. The "how to recover" literature is often enmeshed in the personal accounts literature, and includes descriptions of the things that are needed in order to maintain mental health. The next topic in this review is types of recovery research, of which the author describes and gives examples of five: models, definitional studies, outcome studies, measurement of recovery and healing, and measures related to recovery. Finally, the use of recovery literature is discussed as a relatively new way of guiding mental health system policy.

Sands, J.D., & Wehmeyer, M.L. (Eds.). (1996). *Self-determination across the life span: Independence and choice for people with disabilities*. Baltimore, MD: Paul H. Brookes Publishing Company, Inc.

This book examines the possibility of seamless transition from youth to old age for people with disabilities. It reviews historical and personal perspectives in relation to self-determination. Sands and Wehmeyer examine self-determination as an educational outcome for children, youth, and adults. In their perspective, they emphasize the assurance of self-determination as a goal in early childhood and elementary education by promoting it in school reform, individualized planning, and the curriculum, as well as in the transition process to adulthood. They examine trust issues and self-determination, as well as parents' perspectives. In their view, "learning with purpose" must be a lifelong process using self-determination skills.

Schwartz, B. (2000). Self-determination: The tyranny of freedom. *American Psychologist, 55*(1), 79-88.
Http://www.swarthmore.edu/SocSci/bschwar1/self-determination.pdf

The author of this article argues that when self-determination (what he describes as unconstrained freedom) is carried to an extreme, it is no longer about freedom of choice, but instead leads to paralysis and self-defeating tyranny. He goes on to point out that it is self-determination with certain rules and constraints that leads to well-being and optimal functioning. Using rational-choice theory, he argues that there are no true preferences, and too much freedom leaves people indecisive about what to do and why. Thus, by aspiring to self-determination without constraint, we are actually aiming towards chaos, dissatisfaction, and paralysis.

Sprague, J., & Hayes, J. (2000). Self-determination and empowerment: A feminist standpoint analysis of talk about disability. *American Journal of Community Psychology, 28*(5), 671-695.

This paper offers a feminist critique of language used about self-determination and empowerment in the context of disability, focusing on the case of developmental disabilities. Self-determination and empowerment have become key concepts among those committed to the cause of people with disabilities. Despite all the attention being paid to the importance of self-determination and empowerment for people with disabilities, however, there has been little critical discussion of what the concepts mean, much less the potential of a relationship between them. In this paper, the authors begin by identifying major themes in the feminist critique of knowledge, and then, reveal how these themes permeate discourse about self-determination and empowerment. They also identify trends in the literature that can be used to develop an alternative to current ways of thinking.

Tower, K.D. (1994). Consumer-centered social work practice: Restoring client self-determination. *Social Work, 39*(2), 191-196.
Http://www2.plattsburgh.edu/acadvp/libinfo/library/er/swk308r22.pdf

This article describes the trend in social work practice to support self-determination among clients with disabilities. The author begins by describing the philosophy of consumerism as opposed to the passive receipt of services, and how it grew from several social movements from the 1960s and 1970s. She then focuses on comparing the independent living model to the medical model, specifically addressing how the former model promotes self-determination and autonomy and the latter encourages dependence. The author then goes on to describe current trends in the empowerment movement. Specifically, she mentions survival groups and clubhouses geared towards independence for people with disabilities, the ADA, and programs for the aged that focus on the exchange of services among this group. Finally, the author discusses the importance of advocacy and the adoption of a client-centered orientation in social work. Through the encouragement of social workers, people with disabilities should be able to take "purposeful action to improve their conditions through self-advocacy and organization with peers."

Turner-Crowson, J., & Wallcraft, J. (2002). The recovery vision for mental health services and research: A British perspective. *Psychiatric Rehabilitation Journal, 25*(3), 245-254.

This paper provides an overview of the history of the "recovery vision" in the U.S., Britain, and other countries. It also explores the relevance of this vision to British mental health services, and discusses concerns raised by some individuals with mental illness about recovery concepts. The recovery themes delineated in the article include: being believed in and encouraged by at least one other person; developing perspective on the past; taking personal responsibility for one's life; acting to rebuild one's life; developing valued relationships and roles; changing other people's expectations; gradually gaining a sense of greater well-being; developing new meaning and purpose in life; and persevering through pain, struggle, symptoms, and other setbacks or difficulties. The essential point is made that, "whether mental health problems are viewed in biological, social, psychological, or spiritual terms, recovery is still a necessary process." The article also lists a number of recovery-oriented resources and outlines ways in which Britain can move forward in exploring and implementing a recovery paradigm.

What Helps and What Hinders Self-Determination

Bluebird, G. (2000). *Participatory dialogues: A guide to organizing interactive discussions on mental health issues among consumers, providers, and family members.* **Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.**
Http://www.mentalhealth.org/publications/allpubs/SMA00-3472/SMA00-3472.pdf

This monograph was written to encourage partnerships between people with psychiatric disabilities, practitioners, families, and other stakeholders in the public mental health system by teaching the concepts of "participatory dialogue." It presents simple, concise information that anyone can use to initiate a dialogue between various stakeholders. Step-by-step instructions, tips, and vignette examples are given to illustrate methods and results of participatory dialogue. Topics such as organizing a committee, choosing a title and theme, selecting a location and participants, technical considerations, time limits and timeframes, and evaluation of results all are detailed. Although a forum for equal exchange is the goal of this process, the fact that people with psychiatric disabilities should take the lead in organizing and facilitating the dialogues is a fundamental principle of the monograph.

Bureau, B. (1993). *Empowerment is more than a buzzword, it's a way of life.* **Lawrence, MA: National Empowerment Center.**

This brief paper presents four areas of empowerment as they relate to mental health clients and psychiatric survivors: (1) the obstacles to empowerment, (2) some paths toward empowerment, (3) what empowerment means to other civil rights groups, and (4) what empowerment means to people who are now thriving. It's written in an accessible format and is an easy read for people who are just becoming aware of empowerment. The focus of the paper is on access to information regarding medications, benefits, absence of civil rights, speaking out about sexual and physical abuse and trauma, sharing coping and recovery strategies, creating a backup plan, and other bytes of information. This paper is a good place for people to begin their awareness, and can lead them to seek out additional information on recovery.

Carpinello, S.E., Knight, E.L., Markowitz, F.E., & Pease, E.A. (2000). The development of the Mental Health Confidence Scale: A measure of self-efficacy in individuals diagnosed with mental disorders. *Psychiatric Rehabilitation Journal, 23*(3), 236-243.

This paper introduces the development and testing of a scale that measures self-efficacy beliefs among people with psychiatric diagnoses, which focuses on how confident they are that they could do something to help themselves deal with some common mental health difficulties (e.g., be happy, get support, deal with feeling lonely). The authors tested this scale by using participation and non-participation in mental health self-help groups as the comparison, and they found that the scale reliably measures mental health related efficacy. In correlational analyses, they found that there are positive associations between participating in self-help groups and self-efficacy.

Chamberlin, J. (1978). *On our own: Patient-controlled alternatives to the mental health system.* **New York: Hawthorn.**

In this book, the author shares her personal experiences and the lessons she has learned from being in the mental health system. It makes a compelling case for patient-controlled services as an alternative to the institutions that can destroy the confidence and independence of their clients. This is a work of great hope and optimism; Chamberlin argues for what can be done. Her book has enabled many who have borne psychiatric labels to turn their lives around, and to live happily, creatively, and meaningfully.

Chamberlin, J. (1995). Rehabilitating ourselves: The psychiatric survivor movement. *International Journal of Mental Health, 24*(1), 39-46.

In this narrative paper, the author presents the views of users of psychiatric services with respect to psychiatric rehabilitation. She acknowledges that no one person can represent all views of all organizations throughout the world, but she expresses herself as a psychiatric survivor representing her organization: U.S. National Association of Psychiatric Survivors. She describes her own experiences in mental health services settings, as well as her work in the movement. She goes on to describe peer-run services, using Ruby Rogers Center in Cambridge, Massachusetts as a model, mentioning others like it.

Chamberlin, J., Rogers, E.S., & Langer Ellison, M. (1996). Self-help programs: A description of their characteristics and their members. *Psychiatric Rehabilitation Journal, 19*(3), 33-42.

This study, designed with the assistance of an advisory board of people with psychiatric disabilities, sampled members of six self-help programs across the country that were deemed to represent a broad scope of peer-run programs. Using the results from one-on-one surveys, the authors report on program descriptions, demographics, service utilization, involvement in program, quality of life, self-esteem, social supports, satisfaction with participation in the program, and community activity.

Charlton, J.I. (1998). *Nothing about us without us: Disability oppression and empowerment.* Berkeley, CA: University of California Press.

The author enlightens readers to the disability rights movement worldwide and purports that disability oppression is rooted in degradation, dependency, and powerlessness. This is the first book that provides a theoretical overview of disability oppression and describes its similarities to and differences from racism, sexism, and colonialism. His analysis in the book is based on 10 years of interviews with disability rights activists throughout the Third World, Europe, and the United States. The individual stories evoke self-reliance and empowerment as creating a resistance to disability oppression that is emerging worldwide. He makes it clear that, although disability rights is a

latecomer to the liberation movement around the world, it has a history and political philosophy of self-determination.

Copeland, M.E. (n.d.). *Being the expert on yourself.* Retrieved October 30, 2001, from http://www.mentalhealthrecovery.com/read18.html

This short article, written by a woman diagnosed with bipolar disorder, stresses the idea that each individual knows himself or herself better than anyone else. The author advocates that it is important to "listen to yourself to determine what is best and right for you." She also states that it is important to ask yourself questions about how you're feeling and what you know about yourself in order to feel as good as possible. She concludes with a list of ideas to consider that may help people to know themselves and their needs more fully, especially when confronted with advice from many different sources.

del Vecchio, P., Fricks, L., & Johnson, J.R. (2000). Issues of daily living for persons with mental illness. *Psychiatric Rehabilitation Skills, 4*(3), 410-423.

This article argues that poverty-related issues and unmet basic needs (including housing, employment, health care, and education) are some of the greatest barriers that people with psychiatric disabilities face in building a quality life. Reductions in public assistance programs, as well as continued societal stigma and discrimination, further reduce individuals' access to health care, housing, employment, and a range of essential community services. The point is made that – with client-centered community supports, systems integration, and peer-operated services – persons with mental illnesses can build their own futures, realize their dreams and aspirations, and make contributions to society.

Granger, B., & Gill, P. (2000). Strategies for assisting people with psychiatric disabilities to assert their ADA rights and arrange job accommodations. *Psychiatric Rehabilitation Skills, 4*(1), 120-135.

This article is based on a national study on job accommodations for people with psychiatric disabilities. It describes basic information about the ADA and the issues of disclosure, in response to an earlier study which found that persons with psychiatric disabilities often do not know about the ADA and are wary of disclosing. It also provides practical information about the role of employment support groups in facilitating communication of accommodation needs effectively. In addition, website resources are provided.

Hagner, D., & Marrone, J. (1995). Empowerment issues in services to individuals with disabilities. *Journal of Disability Policy Studies, 6*(2), 17-36. Http://www.empowermentzone.com/empower.txt

The authors of this article discuss empowerment as it relates to the current service system. In their review of the literature, they found that there has been a variety of confusing meanings and interpretations of empowerment. However, the opposite is true of disempowerment in the delivery of services across all disability groups, where there appears to be consensus that services often disempower people served. The authors identify five basic service issues where people in all disability groups are powerless: service convenience, professional caution, professional expertise, client compliance, and professional relationships. They examine these and explain how the current service system limits empowerment. They include a presentation of elements of a system that overcomes these limitations and promotes empowerment.

McLean, A. (1995). Empowerment and the psychiatric consumer/ex-patient movement in the United States: Contradictions, crisis and change. *Social Science Medicine and Medicine, 40*(8), 1053-1071.

The author begins this article with a short background on the psychiatric consumer/ex-patient movement, and then, discusses the conceptual problems in defining empowerment. She presents results from an ethnographic study of one such alternative program, called "The Quad," and attempts to explain the discrepancy between the program's philosophy of empowerment and its actual practices. Utilizing these data, the literature, and interviews with consumer/survivor leaders nationwide, the author identifies discrepancies between the terms "empowerment" and "consumer empowerment," and the social barriers imposed by the local structural conditions under which the program operated. She found that the disparity between The Quad's empowerment ideology and its actual practices resulted from several sources, such as specific local structural conditions, the organization's emphasis on advocacy over self-help, and the background and values of the coordinators hired to run the program. These conditions and their effects on each other worked to diminish accountability to users and efforts to empower them. This article identifies potential pitfalls to which other peer-run programs may be vulnerable, including reproducing conditions that maintain participants as "passive consumers" instead of "proactive producers."

National Mental Health Consumers' Self-Help Clearinghouse. (2000). *Technical assistance guide: Self-advocacy.* Philadelphia, PA: Author.
Http://www.mhselfhelp.org/freedom/pubsa.pdf

This technical assistance guide provides an overview of the attitudes and skills needed to improve self-advocacy abilities. It lists a number of resources that can be used to further refine one's skills and attitudes, as well as locate information to help overcome specific obstacles to self-advocacy. Examples of desired attitudes/behaviors include believing in yourself, being assertive, and managing your anger. Problem-solving strategies are outlined such as educating yourself, identifying your rights, breaking down the problem, and developing a solution. The guide also describes how to advocate for oneself on the telephone, in writing, and in person.

Nelson, G., Lord, J., & Ochocka, J. (2001). Empowerment and mental health in the community: Narratives of psychiatric consumer/survivors. *Journal of Community & Applied Social Psychology, 11,* **125-142.**

The purpose of this study was to explore the experiences of empowerment and mental health among people with psychiatric disabilities, and to understand these experiences in terms of the emerging empowerment paradigm. The article begins by clarifying concepts of empowerment and mental health, and discussing relevant research in these areas. Focus group interviews with 59 stakeholders (i.e., clients, staff, managers, family members, and volunteers) and in-depth stories of six people with mental illness (through 30 interviews) served as the study's database. All of the participants in the interviews were associated with either a mainstream community mental health agency or a self-help organization. The results of this qualitative study suggest pathways that connect empowerment and mental health, and point to the importance of the community context for mental health and empowerment. The findings also reveal empowerment processes that occur at multiple levels which are critical for recovery. The authors put forth the view that a community narrative of empowerment sets the stage for supportive relationships, empowering organizations, and welcoming communities, all of which are conducive to positive mental health.

Neugeboren, J. (2001). *Transforming madness: New lives for people living with mental illness.* **Berkeley, CA: University of California Press.**

This is the second book written by the author of "Imagining Robert" (regarding his brother with schizophrenia, who spent much time in terrible conditions in locked wards). In his second book, through interviews with people living with mental illness, the author effectively portrays that many people with this disability lead successful lives and sheds new light on their lives and abilities. The essence of Neugeboren's book is that it's the presence of hope that brings people with mental illness to productive living. The book has been described as informative, inspirational, inquisitive, and profound.

Rogers, J.A. (1995). Work is the key to recovery. *Psychosocial Rehabilitation Journal, 18*(4), **5-10.**

This article, written by a man who went through the experience of being prevented from seeking employment due to a psychiatric diagnosis, describes various successful peer-run and other vocational models. He also describes some specific research programs which promote work and recovery for people with psychiatric disabilities, including, ACT-NOW, Project OATS, ACCESS, the Employment Project, and the Boston University Center for Psychosocial Rehabilitation.

Rogers, S. (1998). To work or not to work: That is *not* **the question.** *Journal of Psychosocial Nursing, 36*(4), **42-46.**

This paper discusses issues related to work and recovery. Three key points are addressed in this article. The first is that even though employers in the community mental health field are expected to hire people with psychiatric disabilities, employers in the private sector quite often are not, making it much harder for these individuals to find jobs in a wide range of areas (especially ones in their particular field). Often, people with psychiatric disorders find it extremely difficult to return to any job after an acute episode. The second main point in this article is a positive one. There are many peer-run agencies throughout the country that offer volunteer and employment opportunities, job training, placement services, and mentorship experiences. Finally, the third key point in this paper involves addressing "Swiss-cheese" resumes that are common among people with mental illness.

Sartori, G. (1996). *Toward empathy: Access to transition houses for psychiatrized women*. Whitehorse, Yukon: Second Opinion Society. Http://www.mindfreedom.org/madmarket/

This manual, authored by a woman who identifies as a psychiatric survivor, features women's personal stories, general principles of supportive approaches to care, guidelines for specific crisis scenarios, and alternative resources. The appendix includes more than 50 pages on psychiatric drugs (including tips on quitting), plus sections on peer counseling, breathing exercises, herbs, a brief history of the psychiatric survivor movement, resources for transition houses, and a reading list.

Siebert, A. (1996). *The survivor personality*. New York: Perigee Books/Berkley Publishing Group. Http://www.mindfreedom.org/madmarket/

When faced with adversity, tragedy, or just "bad karma," what makes one person crumble, another survive, and another thrive? Al Siebert first became interested in this question when he discovered that World War II combat survivors were less like Sylvester Stallone in "Rambo" and more like Alan Alda's Hawkeye (the irreverent "M*A*S*H" surgeon.) Years of subsequent research taught Seibert that those who survive - and thrive - often respond to challenge with humor, wisdom, and mental and emotional flexibility. No, life isn't fair, but Siebert offers tricks to regaining stability in a difficult world.

Spaniol, L., Gagne, C., & Koehler, M. (1997). Recovery from serious mental illness: What it is and how to assist people in their recovery. *Continuum, 4*(4), 3-15.

In working more effectively with people with psychiatric disabilities, the authors of this article address four major questions related to helping people recover. These questions are: 1) What is recovery?; 2) What are people recovering from?; 3) What is the impact

of what people are recovering from?; and 4) How can people be assisted by professionals in their recovery?

Spaniol, L., & Koehler, M. (1994). The foundations of coping for people with psychiatric disability. *Innovations and Research, 3*(2), 1-2.

In this short editorial, the authors describe four basic foundations for the coping process. These are: hope, acceptance, courage, and humility.

Valimaki, M. (1998). Psychiatric patients' views on the concept of self-determination: Findings from a descriptive study. *Journal of Clinical Nursing, 7*(1), 59-66.

The author of this pilot study used content analysis of unstructured interviews to examine the views of people with psychiatric disabilities in long-term hospital settings on the concept of self-determination. She found that of the 72 patients who participated in the study, only one-third were familiar with the concept, with the other third completely unfamiliar. Fifty-two of the research participants described their definitions and views of self-determination, regardless of whether or not they were familiar with the concept. Upon analysis, the author found that there were two central aspects to the definitions: an intrapersonal aspect, where it was defined in relation to the participants themselves or their activities; and an interpersonal aspect, where they focused on their relationships with others.

Valimaki, M., & Leino-Kilpi, H. (1998). Preconditions for and consequences of self-determination: The psychiatric patient's point of view. *Journal of Advanced Nursing, 27*(1), 204-212.
Http://www.blackwell-synergy.com/servlet/useragent?func=synergy&synergyAction=showFullText&doi=10.1046/j.1365-2648.1998.00504.x

In this interview study of 72 people with psychiatric disabilities in long-term hospital settings in Finland, the authors studied the preconditions for and the consequences of self-determination from the patients' points of view. Research participants were asked questions about what is required of them to obtain information, make decisions, give consent, refuse, and express opinions about their treatment, and what the consequences are of doing so. Using qualitative content analysis, the authors found that the responses concerning preconditions fit into three categories: 1) self-determination is an irrelevant issue in their lives due to absence of rights; 2) self-determination requires no special preconditions, as they have the same basic rights shared by all citizens; and 3) certain preconditions were necessary for self-determination. In the last category, participants shared four types of comments: 1) the person must have the ability to make decisions; 2) the person must be active and work on his/her own initiative; 3) the person must be obedient and do what he/she is asked to

do; and 4) the person's disability is a precondition for self-determination. In terms of the consequences of self-determination, participants described both positive and negative impacts on well-being and mood. They also described the consequence of providing meaning to their lives. On the other hand, they also expressed that their opinions were not always respected and that their views sometimes were laughed at or ignored by staff. Similarly, some said that they feared punitive interventions or revenge if they expressed their opinions.

Wehemeyer, M.L. (1996). Student self-report measure of self-determination for students with cognitive disabilities. *Education and Training in Mental Retardation and Developmental Disabilities, 31*, 282-293.
The Arc's Self-Determination Scale was developed as a student self-report measure of self-determination as an educational outcome in order to enable students with cognitive disabilities to become more self-determined. It works by allowing them to evaluate, with supports and accommodations, their beliefs about themselves and their self determination, work collaboratively with supports to identify areas of strength and limitations as related to self-determination goals, and self-assess progress in self-determination over time. In addition, it can be used as an assessment tool for researchers. The four domains that the scale covers are autonomy, self-regulation, psychological empowerment, and self-realization. The autonomy domain has two sub-domain areas: independence and acting on the basis of preferences, beliefs, interests, and abilities. The self-regulation's two sub-domains are: interpersonal cognitive problem-solving and goal setting and task performance.

Wolf-Branigin, M., & Sawilowsky, S. (1994). Perceived importance of self-determination factors by consumers in substance-abuse treatment. *Perceptual and Motor Skills, 79,* 284-286.

In this study, 40 people with mental illness in substance abuse treatment were given a questionnaire that asked them to rank 24 factors in terms of how well they promote self-determination. Analyses showed strong agreement among the research participants on the importance of these factors. They found that self-confidence, positive attitude, listening skills, and assuming responsibility were identified as the four most important factors promoting self-determination. Using humor, the availability of transportation, and having a role model were perceived as least important.

Zinman, S., Harp, H., & Budd, S. (Eds.). (1987). *Reaching across: Mental health clients helping each other.* Riverside, CA: California Network of Mental Health Clients.
Http://www.mindfreedom.org/madmarket/

This handbook was written for individuals interested in starting or improving programs that truly empower people with psychiatric disabilities. The large-format, clearly-laid-out manual contains sixteen concise, practical articles by experienced psychiatric survivor

leaders. The theme is about staying true to the movement's roots, while at the same time, creating effective, accountable self-help projects. There are five parts: Governance/Administration, Personnel Issues, Membership Outreach, Fundraising, and Working With the Community. Issues covered include: volunteer training and hiring; creating a democratic structure; accounting and fund raising; and being a board member. There also are tips about bridge-building to the disability, African American, Hispanic, and rural communities. Linking the future with the past, photos and posters of the psychiatric survivors liberation movement going back 25 years are sprinkled throughout. The late Howie The Harp wrote two chapters and co-edited the book with Sally Zinman. Other contributors include Judi Chamberlin, Paul Engels, Ron Waters, Pat Risser, Ginny Risser, Mary Carley, Carlos Perez and Sybil S. Seckinger.

Self-Determination in Treatment Decisions and Settings

Bentley, K.J. (1993). The right of psychiatric patients to refuse medication: Where should social workers stand? *Social Work, 38*(1), 101-106.

Using legal principles, case law, and social work's Code of Ethics, this discussion argues that, for legal, empirical, and ethical reasons, social workers should be proponents of the right of people with mental illnesses to refuse medication. Using a framework of the social work profession's two main value positions – self-determination and respecting the dignity and uniqueness of individuals – the author addresses the differences among competence, commitment, and mental illness; the right to privacy; and the prohibition against cruel and unusual punishment. Using these arguments, the author presents a position for the social work profession that, she says, stands for balance and common sense.

Cohen, D. (Ed.). (1990). Challenging the therapeutic state: Critical perspectives on psychiatry and the mental health system [Special issue]. *The Journal of Mind and Behavior, 11*(3/4), 1-328.
Http://www.mindfreedom.org/madmarket/

Part One of this special publication of *The Journal of Mind and Behavior* compiles key articles on alternative "mental health," along with critical perspectives of psychiatry, psychology, and the "medicalization of life." Twenty dissident academic researchers, whistle blowing professionals, and psychiatric survivors join forces. In this issue, Peter Breggin documents links between neuroleptic drug use and a wide variety of brain damage. Ronald Leifer explains how the medical model allows for psychiatry to become an extra-legal form of social control. Phyllis Chesler examines 20 years of fall-out since her book *Women & Madness.*

Duncan, B.L., & Miller, S.D. (2000). *The heroic client: Doing client-centered, outcome-informed therapy.* San Francisco: Jossey-Bass.

The authors, psychologists, challenge the traditional focus on diagnosis, as well as quick-fix treatment strategies and over-reliance on medications, exposing them as practices that can diminish the role of clients and hasten therapy's extinction. They advocate for the often neglected but crucial factor in therapeutic success – the innate resources of the client. The book uses extensive research and case studies to show the power of enlisting the client as a partner to make therapy accountable.

Fetterman, D.M. (2002). Empowerment evaluation: Building communities of practice and a culture of learning. *American Journal of Community Psychology, 30*(1), 89-102.
This invited address discusses empowerment evaluation, which fosters improvement and self-determination through the use of evaluation concepts, techniques, and findings. The article begins by defining empowerment evaluation and lists a wide array of settings and programs that have adopted this technique. The author then gives an overview of the three steps to empowerment evaluation: establishing a mission, taking stock, and planning for the future. In conclusion, the author discusses communities of practice, theories of action and use, and the culture of learning and evaluation.

Francher, R. (1995). *Cultures of healing.* New York: Free Press.

This book consists of detailed analyses and critiques of four influential American cultures of therapy: psychoanalysis, behaviorism, cognitive therapy, and biological therapy. It emphasizes how heavily concepts and methods are determined by cultures rather than by empirical data. It shows that all cultures of psychotherapy embody certain tacit assumptions as to what constitutes mental health and illness, on the one hand, and what constitutes desirable life and undesirable stress, on the other hand.

Granger, B. (2000). The role of psychiatric rehabilitation practitioners in assisting people in understanding how to best assert their ADA rights and arrange job accommodations. *Psychiatric Rehabilitation Journal, 23*(3), 215-223.

As part of a national study on job accommodations, 20 focus groups in 10 states were conducted with people from one of two groups: people with a psychiatric disability who had disclosed their disability, used a job coach, and had arranged for one or more accommodations; or people with a psychiatric disability who were currently employed, found their jobs without assistance, and may or may not have disclosed or negotiated job accommodations. Some key findings from these focus groups were: 86% of all research participants were unfamiliar with either the ADA or the notion of job accommodations; both groups had concerns about being treated differently after

disclosure; most participants agreed that disclosure to co-workers was not a good idea; participants with job coaches thought their support was very valuable; and many participants spoke of the need for education for employers and co-workers regarding accommodations. More specific findings are outlined in the paper, as well as suggestions for practice implications.

Hoge, S.K. (1994). The Patient Self-Determination Act and psychiatric care. *Bulletin of the American Academy of Psychiatry Law, 22***(4), 577-586.**

This article describes legal aspects of the Patient Self-Determination Act (PSDA) as it relates to psychiatric care. It goes over the requirements of the PSDA, which briefly are to provide summaries to patients of existing state law concerning advance directives, to develop and to provide to patients institutional policies regarding advance directives, and to educate the public about advance directives. The author goes on to explain that the PSDA requires that information about existing state law must be publicized to patients and the public, institutions must develop and maintain policies on advance directives that facilitate their use, and must educate their staff and the community about advance directives. Summaries of state law and institutional policies must be given to people at the time of admission to the hospital, hospice, or nursing home, before initiation of home health care, or when enrolling in an eligible health care organization. If the person is "incapacitated" at the time of admission due to a mental disorder and is unable "to receive information" or "articulate whether or not he or she has executed an advance directive," then this information must be given to a family member or surrogate. Once he or she has regained capacity, this information must be given to the individual with mental illness. The author goes on to describe some of the difficulties in implementing the PSDA, including the difficulties of providing a consistent state summary, developing institutional policies, and interpreting advance directives. He concludes the article by discussing some specifics about treatment decisions, refusal, facilitation, and psychiatric hospitalization.

Johnstone, L. (2000). *Users and abusers of psychiatry: A critical look at psychiatric practice* **(2nd ed.). London: Routledge.**
Http://www.mindfreedom.org/madmarket/

Using real-life examples and her own experiences as a clinical psychologist, the author argues that the traditional way of treating mental illness can often exacerbate people's original difficulties leaving them powerless, disabled, and distressed. In this completely revised and updated second edition, she draws on a range of evidence to present a very different understanding of psychiatric breakdown than that found in standard medical textbooks. *Users and Abusers of Psychiatry* is a challenging but ultimately inspiring read for all who are involved in mental health – whether as professionals, students, service users, relatives, or interested lay people.

Manning, S.S., & Gaul, C.E. (1997). The ethics of informed consent: A critical variable in the self-determination of health and mental health clients. *Social Work in Health Care, 25*(3), 103-117.

The authors of this article argue that informed consent as a way to enhance self-determination is not currently working properly. They state that while the form is there, the commitment to practicing a consent process based on the values of self-determination is lacking. In this paper, they go over the elements of informed consent, identify issues that reflect the proper "spirit" in which consent should be obtained, and recommend future actions to enhance self-determination in practice. They discuss the true "spirit" of informed consent as a process involving legal and moral dimensions, correct timing, proper assessment of competency, and the integration of cultural factors. It also involves the issues of awareness, understanding, relationship, and attitudes applied to daily practice. Also important to self-determination in relation to the consent process, according to the authors, is a sharing of power in the relationship, non-complex language of forms, legal emphasis, and a sense of community.

Moxley, D.P., & Freddolino, P.P. (1990). A model of advocacy for promoting client self-determination in psychosocial rehabilitation. *Psychosocial Rehabilitation Journal, 14*(2), 69-82.

This article outlines the Client Support and Representation (CSR) model of advocacy services. The authors begin by discussing the theoretical rationale for CSR, and then, overview the project that was designed to implement and evaluate this model through a field test of 473 clients who were about to be transferred or discharged from different types of psychiatric facilities and residential programs. The CSR advocacy intervention involved setting up a new division in an existing public interest law firm that served people with either psychiatric or developmental disabilities. Six new staff members provided CSR services to 222 randomly assigned participants in the advocacy intervention. The process of CSR advocacy involved seven major processes: 1) Engagement or proactive linkage with people with disabilities; 2) Advocacy needs assessment where self-perceived needs of clients are assessed; 3) Setting objectives and identifying tasks through formulating a plan together; 4) Maintaining relationships across space and time, including weekly contact no matter where clients are located; 5) Problem-solving and ongoing needs assessment; 6) Monitoring of problem resolution; and 7) Evaluation of the extent to which clients were satisfied with problem resolution. In this evaluation, the authors identified nine goal achievement problem areas, where there was general success in all areas. Their highest rate of success was in the area of income and benefits, and the lowest was in employment. Finally, the authors discuss how this model could fit into the psychosocial rehabilitation field.

Newnes, C., Holmes, G., & Dunn, C. (Eds.). (1999). *This is madness: A critical look at psychiatry and the future of mental health services.* Llangarron, Ross-on-Wye: PCCS Books, Ltd.

This book is a comprehensive critique of the contemporary British psychiatric system. In turn critical, strident, scholarly, personal, moving, and ultimately hopeful, it brings together the views of professionals and service users. It is an attempt to develop a more effective, respectful, and humane mental health system. In this volume, users of services, professionals, and academicians come together to explore the roles and practices of the mental health system, its place within society, and the experiences of those in the system. The authors discuss the history of psychiatry, the validity of diagnostic systems, and the value of traditional medical and alternative approaches to emotional distress and crisis. Recent changes in mental health legislation and their likely impact on the future shape of mental health services are presented in a way that is accessible to lay readers, students, and mental health practitioners alike.

Rothman, J., Smith, W., Nakashima, J., Paterson, M.A., & Mustin, J. (1996). Client self-determination and professional intervention: Striking a balance. *Social Work, 41*(4), 396-405.

This qualitative study was designed to look at the range of directiveness modes or helping strategies that social workers use in working with clients. The authors came up with a 4-point continuum of directiveness, which were reflective, suggestive, prescriptive, or determinative. Respondents were asked to give four specific vignettes, one for each of the four helping strategies, including both basic case information and conditional factors that led to their use of the particular method. Both the basic information and the conditional factors were coded, and then, an "ethical suitability review committee" gave judgments on the ethical suitability of the interventions. The study found that a large percentage of the social workers used all four modes of directiveness, and that most vignettes were judged to be ethically suitable. More interestingly, the study found different frequencies of conditional factors in each of the four modes of directiveness. Specifically, in the reflective mode, practitioner factors were very high; in the suggestive and prescriptive modes, client factors were high; in the determinative mode, consequence factors were high.

Russinova, Z. (1999). Providers' hope-inspiring competence as a factor optimizing psychiatric rehabilitation outcomes. *Journal of Rehabilitation, 65*(4), 50-57.

This article examines the relationship between hope and recovery for people with psychiatric disabilities by defining each concept separately, and then, introducing a new model on how they relate to each other. Using this perspective, the author describes the concept of service providers' hope-inspiring competence and identifies its main dimensions. The author goes on to describe how the ability to inspire and maintain hope can play a central role in the recovery process.

Silverman, H.J., Tuma, P., Schaeffer, M.H., & Singh, B. (1995). Implementation of The Patient Self-Determination Act in a hospital setting: An initial evaluation. *Archives of Internal Medicine, 155*(5), 502-510.

The objective of this study was to investigate the compliance of hospital staff of a 550-bed acute care university hospital with implementing the Patient Self-Determination Act, the effects of the act on how much the patients discuss and prepare advance directives, and variables that influence discussion and preparation of advance directives. They surveyed 219 patients from four different medical services, and conducted a telephone follow-up interview with 57% of them six months after discharge. The investigators found that nurses asked 70% of these individuals about whether or not they had an advance directive, and only 57% recalled this inquiry. Of the 57% of those who received a brochure on advance directives, only 55% reported reading the brochure, and only 2% requested additional information. Fewer than one-fourth of all interviewees had discussions on advance planning while in the hospital, and of those contacted after six months, 39% had discussions and 15% actually prepared an advance directive. The authors also found both race and education level were independent predictors for hospital discussion, while only education level was an independent predictor for preparing advance directives.

Trysnicky, J. (n.d.). *Why consumers should run the show.* Retrieved March 21, 2001 from the Mental Health World Web site: http://mhw.buffnet.net/wwwjudyt17.html

This article, written by an advocacy trainer, former service recipient, and the Executive Director of Housing Options Made Easy, argues that the best services are flexible, provide choices, and are carried out in an individualized and humane way. She points out that the only way needs can be identified is by someone who has gone through the mental health system. She goes on to explain that mental health services need to be identified, planned, developed, and administered by people with psychiatric diagnoses, in order for them to "fit" individuals properly and be effective.

Whitaker, R. (2002). *Mad in America.* Cambridge, MA: Perseus Publishing. Http://www.mindfreedom.org/madmarket/

This book provides a social and medical history of madness in America, from the 17th century to today. In it, medical journalist Robert Whitaker reveals an astounding truth: people with schizophrenia in the United States fare worse than those in developing countries, and quite possibly, worse than asylum patients did in the early nineteenth century. According to Whitaker, modern treatments for people with serious mental illness are just "old medicine in new bottles" and we as a society are deluded about their efficacy. Tracing over three centuries of "cures" for madness, Whitaker shows how medical therapies – from "spinning" or "chilling" patients in colonial times to more modern methods of electroshock, lobotomy, and drugs – have been used to silence

people and dull their minds, deepening their suffering, and impairing their hope of recovery. Based on exhaustive research culled from old patient medical records, historical accounts, and government documents, this haunting book raises important questions about our obligations to people with psychiatric disabilities, what it means to be "insane," and what we value most about the human mind.

Policy & Funding Mechanisms Related to Self-Determination

Geller, J.L., Brown, J.M., Fisher, W.H., Grudzinskas, A.J., & Manning, T.D. (1998). A national survey of "consumer empowerment" at the state level. *Psychiatric Services, 49*(4), 498-503.

In this study, a survey was sent to the Commissioners of Mental Health in all U.S. states, as well as U.S. territories, to inquire about the state's official handling of the policy of least restrictive alternatives, as well as their views on "consumer empowerment and responsibility." This paper reports on the part of the survey related to empowerment and responsibility. In particular, the survey assessed whether empowerment and responsibility were defined in statutes, regulations, or policies, and whether people with psychiatric disabilities or family members were employed in central or field offices of the authority. With a 100% response rate, the authors found that 22 states addressed empowerment, and 16 addressed personal responsibility in a statute, regulation, or policy. In central offices, 27 states had paid positions for individuals with psychiatric disabilities, and 3 states had paid positions for family members. In field offices, half of the states had paid positions for those with mental illness, and 12 states had such positions for family members. They also found a significant positive relationship between the extent of empowerment and the size of the state's overall population and the quality of mental health services in the state.

Jacobson, N., & Curtis, L. (2000). Recovery as policy in mental health services: Strategies emerging from the states. *Psychiatric Rehabilitation Services, 23*(4), 333-341.

This paper discusses the various ways in which the concept of recovery is implemented in the policies and practices of mental health systems in the United States. The paper begins with an overview of the historical background of recovery, and describes the common themes that have emerged across the wide range of its definitions. The authors go on to overview specific strategies that states use to implement the principles of recovery. Finally, they conclude with some key questions about adopting the concept of recovery as a system policy, addressing some advocates' concerns that the recovery movement may become a "new label on an old bottle."

Moseley, C. (1999). *Making self-determination work.* Retrieved March 27, 2002, from the National Program Office on Self-Determination Web site: http://www.self-determination.org/publications1251/publications_show.htm-doc_id=18644.htm

This paper is written about the results of an e-mail survey to the 19 states funded by the Robert Wood Johnson Foundation in 1996 to develop and implement self-determination approaches in services to people with developmental disabilities. The objective of the RWJ initiative is to change the service delivery system to actively involve, support, and encourage people to directly control the services they receive and the resources provided on their behalf. Fourteen of the 19 states responded to the survey with varying results that provide insight into effective system change strategies, bringing people together in coalitions, efficient financial strategies, and employing successful communications strategies including self-determination principles in legislation, regulation, policy planning, and system redesign activities.

Nerney, T., & Shumway, D. (1997). *Beyond managed care: Self-determination for people with disabilities.* Retrieved April 7, 2000 from http://www.unh.edu/rwj/library/bmcpage1.html, http://www.unh.edu/rwj/library/bmcpage2.html

This paper focuses on choices that people with disabilities and family members can make under current funding regulations in order to move towards self-determination. After detailing the four basic principles of self-determination (freedom, authority, support, and responsibility), the authors point out two specific options that extend beyond current service delivery methods: the use of fiscal intermediaries (or controlling dollars without dealing with cash) and independent brokering of formal and informal supports in order to connect people with disabilities to their communities. The authors also present ways in which self-determination strategies could be effective within the current managed care structure, specifically in terms of capitation, utilization management, and restricting choice of providers.

Sabin, J.E., & Daniels, N. (2002). Strengthening the consumer voice in managed care: IV The Leadership Academy program. *Psychiatric Services, 52*(4), 405-406, 411.

This brief article describes the West Virginia Leadership Academy, developed by grassroots consumer organizations with the support of the West Virginia Office of Behavioral Health Services and the Center for Mental Health Services. The Leadership Academy is a collective advocacy training program designed to strengthen advocacy skills of persons with psychiatric disabilities through skills training and practical lessons on improving managed care and the mental health system. The article highlights the Academy's history and reviews its purpose and methodology, giving an excellent overview of the program.

Stringfellow, J.W. (2000). The relationship of participation in a collective advocacy training program to the attitudes toward authority of consumers of mental health services. *Dissertation Abstracts International, 61*(03), 1700. (UMI No. AAT 9965694)

This study focuses on the political empowerment of persons with psychiatric disabilities who are advancing their skills for collective advocacy in preparation for advocacy roles. Persons assessed were participants in the West Virginia Leadership Academy for Consumers and Families. The program consists of formal training events and ongoing networking activities. Geographical and topographical barriers to the continued engagement of participants in the highly rural Appalachian state were overcome by application of financial resources and communication technology. This study analyzed archived data from the program to evaluate participants' attitudes toward authority and the interaction of those attitudes with participation in the program. It was found that consumers of mental health services commencing the training are somewhat less authoritarian in responses to political survey items than the general population. Results suggest that changes in authoritarian responses to political survey items may be non-linear, decreasing significantly after a two-year period of participation, but not among persons with shorter periods of participation. When queried regarding political ideas, participants in the training program responded with expressed uncertainty more frequently than the general population. The frequency of expressed uncertainty decreased significantly among persons who remained active in the training program. The most fundamental outcome of this investigation regarding the relationship of attitudes toward authority to participation in the Leadership Academy training program is the validation of Keiffer's (1984) finding that development as a political advocate involves a changing relationship to authority throughout.

Stringfellow, J.W., & Muscari, K. (in press). A program of support for consumer participation in systems change: The West Virginia Leadership Academy. *Journal of Disability Policy Studies*.

This article describes the content and evolution of the West Virginia Leadership Academy, developed as a collective advocacy training program by grassroots consumer organizations with the support of the West Virginia Office of Behavioral Health Services and the Center for Mental Health Services. The program has been provided nationwide as a service of the Consumer Operated Networking Technical Assistance Center of the West Virginia Mental Health Consumer Association. Policy implications considered in the article include the need to develop human resources of persons directly affected by psychiatric disabilities, so that they may better articulate their perspectives to decision-makers and actively participate in policy decision-making. Policy supporting such development leads not only to products fostering self-determination, but diffuses the dichotomy between those served and those serving, as recipients of policy become participants in the policy development process.