Self-Determination Among Mental Health Consumers/Survivors: Using Lessons from the Past to Guide the Future

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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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<u>**Introduction**</u>

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 19th and early 20th 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-envisions 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

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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

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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.

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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

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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

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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

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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

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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 21st 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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