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

By Steven J. Onken, Ph.D., Columbia University School of Social Work
In consultation with fellow research team members: Jeanne M. Dumont, Ph.D., Wellbeing Project; Priscilla Ridgway, A.B.D., University of Kansas School of Social Welfare; Douglas H. Dornan, M.S., New York State Office of Mental Health; and Ruth O. Ralph, Ph.D., Edmund S. Muskie School of Public Service

Abstract

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

**Introduction**

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

**Conceptualizing Recovery**

An ecologically based conceptual paradigm for organizing and interpreting the phenomenon of mental health recovery is emerging across research findings. There is increasing convergence of defining recovery as the ongoing, interactional process/personal journey and outcome of restoring a positive sense of self and meaningful sense of belonging while actively self-managing psychiatric disorder and rebuilding a life within the community. Recovery is facilitated or impeded through the dynamic interplay of many forces that are complex, synergistic and linked (Onken,
Dumont, Ridgway, Dornan & Ralph, 2002). This dynamic interaction among characteristics of the individual (such as personal attributes), characteristics of the environment (such as basic material resources), and the characteristics of the exchange (such as choice) can promote or hinder the process and outcome of recovery.

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

**Defining Self-Determination**

To say that behavior is self-determined, or determined by the self, is to say that behavior is experienced as autonomous. When we say self-determination, we essentially mean autonomy – self-governance. Self-Determination Theory (SDT) posits that *autonomy* is an essential ingredient of psychological health, growth, vitality, and
well-being (Deci & Ryan, 2000). More specifically, SDT equates autonomy with volition, or, the “desire to self-organize experience and behavior and to have activity be concordant with one’s integrated sense of self” (Deci & Ryan, 2000, p. 231). Autonomy is the co-occurrence of integration and freedom, and is a sense that one’s behaviors are intrinsically motivated and that one’s experiences and life outcomes are determined by the self (Deci & Ryan, 2000).

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

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

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

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

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

1 Center for Mental Health Services Survey and Analysis Branch, CO Mental Health Services, Columbia University Center for the Study of Social Work Practice, Human Services Research Institute, Mental Health Empowerment Project, MO Institute of Mental Health, Nathan Kline Institute Center for Study of Issues in Public Mental Health, National Assoc. of State Mental Health Program Directors National Technical Assistance Center & National Research Institute, NY State Office of Mental Health, OK Dept of Mental Health and Substance Abuse Services.
sponsoring the project and ten state mental health authorities (SMHAs) are collaborating in carrying it out.

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

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

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

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

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

102

UIC NRTC 2003 National Self-Determination & Psychiatric Disability Conference Papers
many commonalities in people’s recovery experiences and opinions. Recovery can be viewed by as process and a product of complex, linked and dynamic interaction among characteristics of the individual (the self/ holism, hope and a sense of meaning & purpose), characteristics of the environment (basic material resources, social relationships, meaningful activities, peer support, formal services, formal service staff), and the characteristics of the exchange (choice/ empowerment, independence/interdependence).

**Formal Service System Highlights**

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

Many of our findings lend further support to shortcomings already identified within the formal system of care. People have basic subsistence needs (such as a livable income, safe and decent housing, and transportation) that “the safety net” does not
meet. Social welfare and mental health programs are fragmented and difficult to access. People do not want to have to deteriorate in order to receive help, nor do they want to lose vital supports when they make progress toward recovery. Psychiatric services can be experienced as coercion and a means of social control, countering individual efforts of recovery. The experience of trauma and abuse was also notable across the focus groups – through the discussion of internalized stigma, the repeated traumatizations by the system, and the historical trauma of past abuse.

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

Our findings also showed that another critical dimension of recovery is consumer/survivor self-help, consumer operated services, consumer/survivor recovery role models, and consumer/survivor movement involvement. The need for a large-scale expansion, funding, support and availability of peer services, such as peer support, education, outreach, role models, mentors and advocates was a common theme across all focus groups. Participants identified the need for alternative services and “experience experts/peer specialists” employed across all levels of mental health service provision. Limitations in funding, geographical availability, participation, and leadership development opportunities as well as a lack of transportation, and controlling and mistrustful professionals hinder such peer support efforts.
Our results also document the crucial role that choice plays in people’s lives, a finding that has special implications for fostering self-determination in the formal service system. Participants are empowered when they make the choices regarding where they live, finances, employment, personal living/daily routine, disclosure, who they associate with, self-management and treatment. But too often quality of life choices seemed outside the realistic reach of many participants. Options are limited, lousy or nonexistent. Participants recounted service providers, professional and family members and communities that responded through the use of coercion, control, restricted access or involvement, discrimination and stigmatization.

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

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

As mentioned earlier, the premise of SDT is that individuals are inherently motivated to proactively extend and integrate their understanding of themselves, others,
and the world around them, and that this is necessary for optimal psychological functioning (Deci & Ryan, 2000; Ryan & Deci, 2000). SDT emphasizes the realization of one’s true nature and that autonomy, competence, and relatedness are the three pillars of such self-actualization of one’s potentials for psychological health and well-being (Ryan & Deci, 2001; Deci & Ryan, 2000). These are minimum requirements for psychological well-being as well as stipulations for social environments which foster thriving and enhance quality of life (Ryan & Deci, 2001).

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

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

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

Beliefs about self-worth involve feelings of loveworthiness, competence, morality, efficacy, and overall goodness, or self-esteem (Park & Folkman, 1997). Perceptions of
control involve one’s beliefs about one’s ability to control important outcomes and, more generally, one’s life destiny (Park & Folkman, 1997). Beliefs about the world include how benevolent the world is and how trustworthy people are, and beliefs about the self in relation to the world are built upon the interaction of one’s beliefs about the world and one’s beliefs about the self. Park and Folkman also hold that global meaning also includes one’s sense of purpose, or more specifically, beliefs that “organize, justify, and direct” one’s striving (1997, p. 119). In the ultimate sense, these beliefs reflect one’s goals, goal striving, and life purpose.

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

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

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

The Social Dimension of Self-Determination within Formal Service Systems

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

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

True partnership, having the sense that you are viewed and respected as an equal, and that the other person will be there through thick and thin, conveys secure relatedness and fosters intrinsic motivation. Having opportunities for choice and
negotiation in selecting a doctor, therapist or case manager, having complete and accurate information on all possible interventions and supports, real collaboration development of individual treatment plans, foster recovery. The focus of the helping relationship shifts to the actualization of the individual through self-determination and choice.

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

The Instrumental Dimension of Self-Determination within Formal Service Systems

Recovery also involves several core instrumental (i.e., concrete) support dimensions. But the conditions placed on receiving instrumental support can undermine self-determination and thus sabotage recovery. Intrinsic motivation, critical to experiencing behaviors as determined by the self, can be undermined by external
rewards (Deci 1971; 1972), threats (Deci & Cascio, 1972), surveillance (Lepper & Greene, 1975), evaluation (Harackeivicz, Manderlink, & Sansone, 1984), and deadlines (Amabile, DeJong, & Lepper, 1976). All have the propensity to shift one’s locus of causality from internal to external, making one feel less like the origin of one’s behavior, and so, less autonomous, and less responsible for it, ultimately, diminishing intrinsic motivation. External motivators like threats and deadlines undermine one’s sense that an activity is self-initiated, and hence, decrease the amount of autonomy experienced during that activity, leaving one’s need for autonomy unfulfilled.

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

Employment offers a way out of this dependency, but unemployment is the norm regarding psychiatric disability, regardless of how strong the desire and how persistent the effort is to get work. People are confronted with a very limited range of jobs, or find themselves underemployed, in stagnant jobs. Even when one is successfully
employed, fear persists concerning how employers and co-workers will react if they find about one’s mental illness. Advanced education and training is seen as a way of improving one’s employment chances, but people lack access to such opportunities. Unemployment, underemployment, exploitation (in the form of volunteer labor), disincentives (loss or threat of loss of benefits), prejudice and discrimination - the loss of meaningful work or student roles - can be accompanied by the loss of core identity component, that of a sense of productivity and purpose.

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

The illness and crisis orientation of the formal system overly medicalizes and pathologizes people's life experiences. In medical model systems every experience, need and concern comes to be viewed as a symptom of a mental illness and in need of control - at the expense of seeing consumers as whole unique individuals. When the system is crisis-oriented, the person's condition has to deteriorate and reach the level of
crisis or emergency before they can receive help. Services emphasize crisis stabilization, medication and medication management, but this alone is too limited a strategy to assist people in achieving recovery.

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

Many systems still rely on coercion and force, such as coerced consent forms, court mandated services, forced medication, mandated connections, and being forced to accept treatment in order to receive other assistance. Staff often relate to consumers paternalistically, controlling by pressure, threats and force. Forced treatment, threats and other forms of coercion serve as external motivators that hinder an internal locus of causality and undermine intrinsic motivation and the ability to relate as a responsible
person. Coercive systems limit and remove choices, and can use treatment, services, and medication as means of social control. Acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference actualizes self-determination, and is not possible in coercive service systems (Sands & Wehmeyer, 1996).

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

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

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

1. **Choice**

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

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

Choice is something that involves a learning curve. People need opportunities for choice-making and to build choice making competencies. Psychiatric services, however, often are experienced as a stripping away of choices, personal control, and decision-making. Dependency is created, self-doubt is fostered, choice-making competencies are lost. Thus a relearning process may need to activated, starting small...
and progressing to more challenging or complex choices as one regains confidence and experiences success. It helps to have support. People may need assistance in recognizing that they do have choices and are capable of making choices. Time and patience must be respected as a person develops choice-making skills. People benefit from knowing about what choices are available and when their choices are being limited.

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

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

UIC NRTC 2003 National Self-Determination & Psychiatric Disability Conference Papers
2. Interdependence

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

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

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

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

Essential within an interdependence paradigm is empowerment. The process of recovery itself also involves empowerment, i.e., an awareness of the circumstances of one’s illness, the desire and will to alter these circumstances, and a feeling that one has the power to effectively recover, due in part to the strength of internal and external resources (Onken, et al., 2002). For individuals recovering from mental illness, self-determination is reciprocally related to empowerment. The empowerment process may serve to cultivate both self-determination and meaning. Through knowledge, awareness, and insight, empowerment puts recovery into the hands of recovering
individuals and groups, allowing them to determine the pathway to mental health for themselves. Empowerment also motivates the recovery process by inspiring hope, and infusing the lives with meaning and purpose, necessary for the strengthening of concept of self, self-direction and self-determination.

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

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

Since the interdependent paradigm accepts people as they are, another core element is to acknowledge and develop supports. We all need and use everyday supports to make our lives more enriched. The same spirit should surround the way we relate to people with psychiatric disabilities. In other words, we need to allow for the unique manifestations brought on by a person's or group's "difference," and to get people the supports that will help them address the presenting problem ands get on with enjoying life. Achieving independence moves from being measured by the quantity of tasks one can perform by him or herself, to that of the quality of life one can have with supports (Zolla 1986). But people with psychiatric disabilities feel they are viewed as source of billing or as a commodity that generates revenues, rather than as unique
individuals with unique needs and personal freedoms. Formal services have an inflexibility, or rigidity, that doesn't match well with changing or dynamic individualized needs. People are fitted into services and programs rather than services and supports being tailored to people. When resources are tied to levels of care or functioning, program guidelines or the funding of certain programs, services that facilitate self-responsibility and recovery can be denied.

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

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

3. **Vital Engagement**

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

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

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

The felt significance of an enjoyed relationship develops initially through one’s attraction to the object. In this regard, rather than being born into meaning, or being forced to make sense of negative experiences, a person can derive a sense of global meaning as it emerges from their positive experiences and vital engagement with the object. This sense of meaning and significance deepens over time, as one continues to engage with the object and is perpetuated in part through one’s membership in a community of practice and interactions with other members of the community (Nakamura & Csikszentmihalyi, 2003). In this regard, mentors, peers, and students
may all serve to invigorate one’s relationship with enjoyable objects or activities. Such interactions with members of the extended community not only enrich and invigorate vital engagement, but promote its evolution over time (Nakamura & Csikszentmihalyi, 2003).

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

People with psychiatric disabilities also describe engagement in advocacy as a means to gaining voice, of moving towards self-determination and recovery. Personal or self-advocacy is integral to self-determination; group or systemic advocacy activities can trigger referent power opportunities. Often advocacy involvement starts by connecting with peers (attending meetings and sharing experiences) and then seeing others undertake advocacy. Being a part of situations in which others engage in
advocacy can trigger one’s own sense of power. Sharing what it is like to experience ignorance, injustice, stigma and inequalities, and validating that these are common occurrences, helps provide people with a sense of being members of the extended community (Nakamura & Csikszentmihalyi’s assertion) and the strength to speak up. Channeling anger concerning injustice give people the energy to seek change, both personal and political. Advocacy involvement can provide purpose and vital engagement when other opportunities, such as employment, are taken away or restricted and/or employment is too difficult to sustain due to the disorder itself, or when a person feels dependent and possibly trapped on government benefits. Advocacy, civic and artistic involvement opportunities also extend beyond the mental health system, but supports to engage in such are rare or nonexistent.

**Conclusion**

We can more fully actualize the ecological context of recovery for people with psychiatric disabilities when we foster self-determination. A recovery-enhancing system is person-oriented, and respects people’s lived experience and expertise. Optimal mental health is achieved when one’s experience is that of being self-determined. Self-determination is encouraged when basic needs for autonomy, competence, and relatedness are met. Such a recovery-focused and autonomy enhancing environment promotes choice-making and self-responsibility. It addresses people’s needs holistically and contends with more than their symptoms. Such an environment meets basic needs and addresses problems in living. It empowers people to move toward self-management of their condition. The orientation is one of interdependence and hope.
with an emphasis on acceptance, positive mental health and wellness. It fosters creative supports and assists people to connect, including mutual self-help. It focuses on positive functioning in a variety of roles, vital engagement in meaningful activities, and building or rebuilding positive relationships. These core elements can serve as the foundation of a system of care that promotes self-determination and recovery for individuals with psychiatric disabilities.
References


