

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

*By H. Stephen Leff, Ph.D., Jeremy Conley, B Phil., Theodora Campbell-Orde, MPA; Valerie Bradley, MA, Human Services Research Institute, Cambridge Massachusetts*

## INTRODUCTION

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

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

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

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

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

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

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

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

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

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

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

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

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

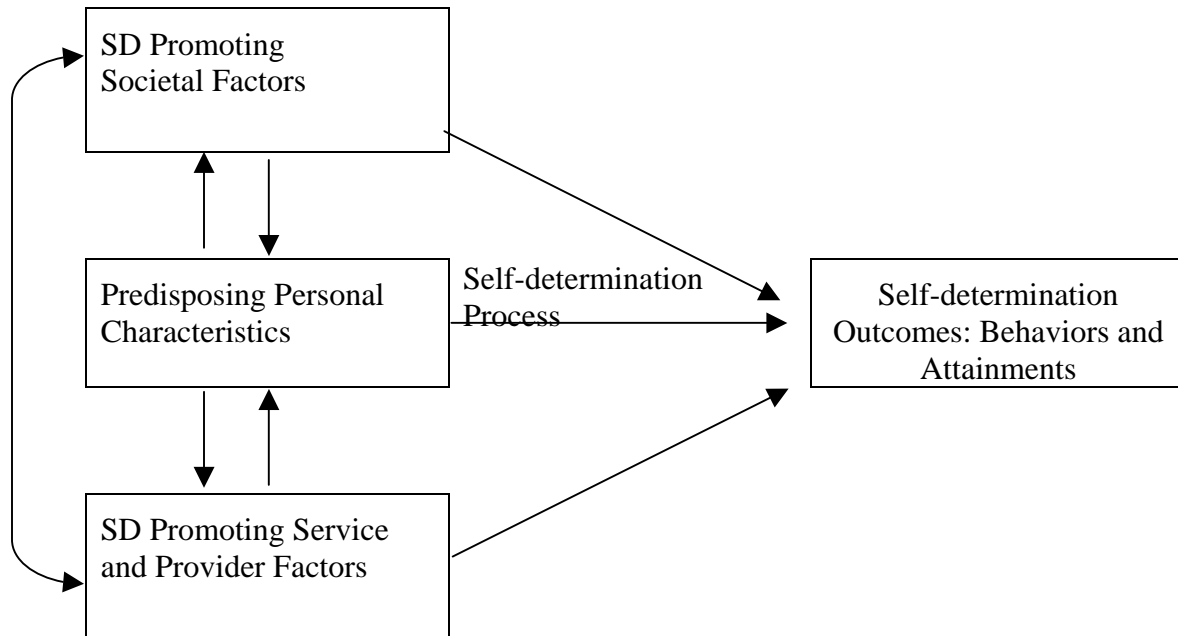


Figure 1. A Simple Logic Model Showing Factors That Affect Self-determination

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

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

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

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

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

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

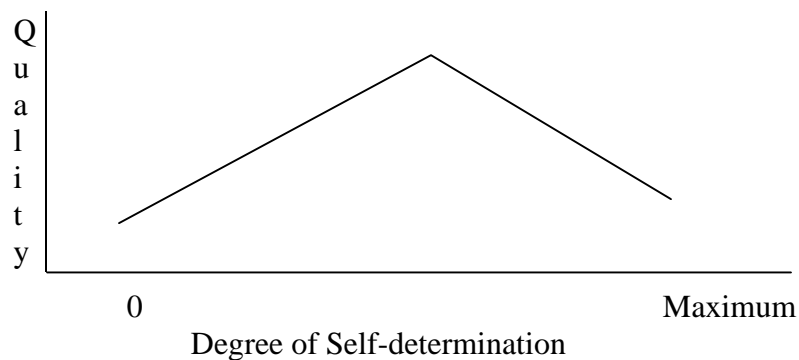


Figure 2. Possible Relationship Between Self-determination and Quality of Life

### **Predisposing Person Variables**

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

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

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

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

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



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

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

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

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

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

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

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

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

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

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

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

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

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

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

Figure 3, shows the ladder of evidence in intervention science. Intervention science is scientific principles applied to the specific task of bringing interventions that are proven safe and effective to consumers.



4. Generalizability 5
3. Effectiveness
2. Development
1. Discovery

Figure 3. The Ladder of Evidence in Intervention Science

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

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

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

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

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

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

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

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

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

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

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

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

But research and evaluation work remains to be done.

We need to

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



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

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

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

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

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