

**STAR Center Summer Teleconference Series:  
Recovery, Self-Determination, Cultural Competence, & Self-Help Tools**

**Topic:** Self-Determination: What does this mean? How do I balance my life's dreams with realistic and achievable goals?  
**Date:** Tuesday, July 21, 2009  
**Speaker:** Jessica A. Jonikas, MA, UIC National Research and Training Center

Thank you, Steve and Carmen, for inviting me to this call today on self-determination, and thanks to everyone who signed on for the discussion. I would like to spend some time reviewing self-determination concepts and theory, as well as a couple of our Center's primary self-determination tools. I'll also be happy to take questions about self-determination and/or our resources.

More and more in public mental health these days, we're hearing talk about self-determination as a part of people's recovery. Self-determination means many different things socially and politically. Generally, when we talk about it in mental health, we're referring to people being supported to make meaningful decisions about their own lives, to control their own finances, and to live, raise families, go to school, and work where they choose and as fits their needs and abilities. In this sense, it is much broader than having choices in treatment and social service settings, although that is an important part of being self-determining. But, self-determination puts the focus on a person's entire life, emphasizing not only treatment goals but life goals as well.

This emphasis on self-determination first appeared in the disability movement for people with developmental disabilities and the elderly. Here, too, the focus was on promoting maximal independence among people with disabilities to live in the community, and receive services and supports of their own choosing. Disability advocates, Tom Nerney and Don Shumway, promote 5 key principles of self-determination (<http://www.centerforself-determination.com/>.) The first is FREEDOM, or the opportunity to choose where and with whom one lives, as well as how to organize the important aspects of one's own life, with help and support along the way. The second is called AUTHORITY, or a service recipient's ability to directly control some of the public dollars spent on his or her public treatment or services. In mental health, we call this principle "self-directed care" or "money follows the person." The third principle is called SUPPORT, or the person with a disability being able to organize services and supports in ways that are unique to that individual. The fourth principle is RESPONSIBILITY or the understanding that people with disabilities will wisely use the public dollars over which they've been given control, and they will participate in meaningful ways in their communities. And the final principle is CONFIRMATION or participation, which is the recognition that individuals with disabilities themselves must be a major part of the re-design of public service systems.

Complementing these self-determination principles has been the introduction of what is called the *New Paradigm of Disability* (<http://www.iglou.com/accessiblesociety/topics/demographics-identity/newparadigm.htm>). This paradigm, or framework, depicts disability as an interaction between the unique characteristics of an individual and the features of his or her cultural, social, natural, and built environments. In this framework, disability does not lie just within people, but instead, disability lies in the interaction between people's personal characteristics and the environments in which they operate. Whereas the old framework views people with disabilities as those who have difficulty functioning because of impairments, the new framework views these individuals as simply needing accommodations in order to function more effectively. Moreover, the new framework acknowledges that people are entitled to accommodations as a civil right.

This new thinking highlights how the environments of people with psychiatric disabilities can be limiting to their self-determination. As such, it directs the search for solutions away from "fixing" people or correcting their deficits, to removing barriers and creating access through accommodations, education, and promotion of self-care and wellness.

With these ideas as a foundation, we can perhaps see how self-determination is responsive to people's diverse cultural backgrounds and perspectives. At first look, we might be concerned that the focus on "self," rather than on the collective or on the group, is not an idea that is readily accepted across cultures. And, indeed, if we were simply advocating that people be left to "go it alone" or to do whatever they want regardless of what others think or need, then self-determination really might not be something *anyone* -- even from Western cultures -- would actually want to embrace.

But, instead, the principles of self-determination recognize that all human beings are interdependent and, as such, it's rare that we make choices that have absolutely no impact on anyone else or on our environment. With its focus on responsibility and participation, self-determination recognizes that all human beings make choices in a context of their family, their elders, their spouses or partners, their friends, and their community (<http://dps.sagepub.com/cgi/reprint/13/2/88>). When we advocate for self-determination principles, we suggest not only that people freely choose how to organize their lives, but that they do this with recovery-oriented services and help from their chosen supporters. As such, when supported to do so, people will generally choose supporters, services, and life roles that are reflective of their cultural and other beliefs, as well as their multiple group memberships such as their gender, age, and/or sexual orientation. We are all unique individuals, but we also live together in a larger context, and self-determination principles and models seek to embrace this richness and complexity.

Unfortunately, as most of us well know, individuals in mental health recovery have not experienced the levels of self-determination achieved by many other groups. Many live in conditions of extreme poverty and cope with a host of unmet needs. Often under-treated and unsupported, they experience higher than average levels of unemployment, homelessness, incarceration, chronic medical illnesses, and social isolation. Society, and unfortunately, many service programs continue to be largely ambivalent about whether people with mental illnesses are capable of knowing what is best for them and making informed choices to become self-determining.

It's hard to think of anything more in conflict with widespread self-determination than these trends. Indeed, it remains the big question of the day as to how we can better take principles of self-determination directly into the lives of people receiving public mental health services. We see that, although increasingly more peer-run programs, traditional rehabilitation programs, and public systems are embracing recovery and self-determination, there is still a big gap between what we believe and what we are able to achieve in public settings. Moving the mountains of institutional thinking held by many providers and families, and even many people in recovery themselves, is going to take ongoing commitment and effort. But, it can be done. It is being done.

In thinking about how it is being done, I want to talk a little bit about self-determination theory (<http://www.psych.rochester.edu/SDT/theory.php>). The word theory might make some of you wonder whether I'm going to cover a bunch of boring concepts that have little relevance for the real world. But, actually, I hope you'll feel that self-determination theory is a very useful tool in considering how human beings become motivated to embrace self-determination and make life improvements or changes, no matter what their disability or life issues.

Self-determination theorists have done multiple studies, discovering that the environment or atmosphere that surrounds us as humans has a huge impact on our ability to make self-determined life choices (Deci & Ryan, 1985). More specifically, the environment in which we make choices is what lies behind our personal motivation and our efficacy to make life decisions and sustain changes. Here again, we see the idea that it's the interaction between a person's unique characteristics and his or her environment that either helps or hinders self-determination.

These studies have looked at people's motivation to do such things as lose weight, quit smoking, control glucose levels, or take medications for long-term illnesses as prescribed (Williams & Deci, 1996; Williams, Freedman, & Deci, 1998; Williams, Grow, Freedman et al., 1996; Williams, Ryan, Rodin et al., 1998).

And the research has shown that there are 2 types of motivation that lead people to make major health-related decisions or changes (Reeve, Nix, & Hamm, 2003; Williams, Freedman, & Deci, 1998). The first is called Controlled Motivation.

Controlled motivation occurs when people feel pressured to engage in decisions or behaviors by other individuals or forces. They may feel pressured to change or engage in services from doctors, providers, family, or friends. They may feel guilty or ashamed if they don't do what everyone expects.

In contrast, the second type of motivation is called Autonomous Motivation. Autonomous motivation exists when people initiate their own decisions and act on them because they personally believe in what they're doing. They self-initiate decisions or life changes, and they endorse them as best. For example, someone who experiences autonomous motivation attends a health education group because she believes it will work and she wants to improve her health, while a person who experiences controlled motivation attends that same group because he feels pressured from others to be healthier and he feels ashamed about not attending.

The importance in this distinction in types of motivation is that research shows that autonomous motivation is the one that results in the most lasting health and behavior changes. And that is pretty intuitive when you think about your own life. I would guess that most of the time, the decisions that have worked out best have been those that you feel most right about in your own heart and mind.

Now, importantly, in these studies of SDT, it also has been found that people are more likely to experience autonomous motivation when the people around them offer what is called autonomy support.

Autonomy support occurs when providers and other supporters understand the perspectives of the person who is trying to recover and become more self-determining. Autonomy support also occurs when supporters acknowledge this person's feelings, offer choices, and provide whatever information is needed to make informed decisions. That sounds a lot like recovery-oriented care. And, as such, when environments are recovery-oriented they also are autonomy supportive, which means that they are more likely to lead people to engage in healthy, self-determined life choices that they personally endorse and want to maintain over the long-term (Williams & Deci, 1996; Williams, Freedman, & Deci, 1998; Williams, Grow, Freedman et al., 1996).

When thinking about how to create autonomy supportive environments for ourselves, our peers, or the people we serve, we can assess several things. First, how well do we feel heard, or make others feel heard if we're supporting peers? Second, are our feelings and beliefs – or those of the people we support -- truly acknowledged, especially cultural beliefs that may be quite different from the perspectives of the majority? Third, do we receive or provide enough information to feel that we are making truly informed choices among many different options, or are we supporting our peers to do so? As part of this, do we have a process to help clarify decisions that have a lot of sensitivity or conflicting values surrounding them, so that we or others can truly make self-determined life

choices? And finally, are we aware of how our own personal characteristics – or those of the people we support -- interact with service and other environments in ways that either promote or impede self-determination?

It can be hard to have open discussions in peer-led and other programs about the extent to which our environments are truly autonomy supportive, and thus, leading to self-determination across cultures. Yet, the degree to which we can wrangle with these issues is the degree to which our environments can support decision-making for change.

Why don't I take a few questions or comments, before moving on to an overview of our Center's primary self-determination tools?

Our Center makes available a series of self-determination tools that have been designed to help people engage in autonomy supportive activities as they self-direct their own lives.

You all received links to two free, downloadable tools. You probably haven't had time to look at them in-depth, so you can feel free to email me after this call to ask questions or get more information.

The first tool is called, "Express Yourself: Assessing Self-Determination in Your Life" (<http://www.cmhsrp.uic.edu/download/sd-self-assessment.pdf>). This tool helps people to consider how much self-determination they have. The user reads statements that indicate high levels of self-determination, and then, they decide how much these statements describe their own life. In this way, the tool serves as a self-determination needs assessment.

Specifically, tool users read each statement and think about whether or not it's true for them. If the statement is true, then they skip it and go on to the next one. For example, there's an item that says, "I decide whether to live alone or with someone else." If this is true for the user, then she would skip it and go to the next statement, which is "I control who can and can't come into my home." Users continue reading items until they find one that is not true for them. They put a check mark next to that item and keep going until they've read and considered all 32 items.

Next, users go back and look at the items they've checked indicating where they do not have as much self-determination as they would like. For these areas, users can visit the suggested web sites to learn about different options to set goals and move forward.

The premise of this tool is that we cannot begin to improve or change our lives until we understand both what's going well and our problem areas that need attention and help-seeking effort.

Express Yourself covers areas where many people in public systems say they have significant unmet needs, including finances, housing, transportation, employment, community integration, medical treatment, and mental health care.

Peer-run programs and rehabilitation centers all around the country are using this tool in different ways. Some use the tool with peers or clients in treatment or service planning to identify areas where self-determination are lacking, and then make person-centered plans based on that information. We've heard from peers who are using the tool independently and then discussing the results with their providers and supporters. One program used the tool to design an entire advocacy course for its peers, while other programs have used it to design education groups where people identify areas of low self-determination and work on skills together to create solutions.

Our Center also has a tool to accompany this assessment called, "This is Your Life: Creating your Self-Directed Life Plan" (<http://www.cmhsrp.uic.edu/download/sdlifeplan.pdf>). We designed this workbook to help peers consider, choose, plan for, and act on a life goal, with supports of their own choosing. It is a next step after using Express Yourself. We designed this workbook to be very encouraging and supportive, especially for people who don't have a lot of life planning experience. The purpose of the workbook is to help users make a plan for their lives over which they have control, working in concert with service providers and other supporters. It takes users through 8 steps to make a person-centered life plan.

The first is consideration of where they are in the change process. They think about whether they're still thinking about it, ready to plan, or ready to act on life change. Second, they go through concrete steps to prepare to make and use their life plan, including consideration of self-care. Next, they think about their circle of support, and who is among their supporters and whether they'd like to add anyone. Fourth, users choose a goal, and then, consider the good and bad things that may happen as a result of change in this life area. When they're ready, they're taken through some very concrete steps to plan for success with their new goal, including recording the goal, listing the specific tasks, considering their obstacles, considering their resources and strengths, and setting target dates by which they will achieve their tasks. They also are taken through a detailed process to make a personal budget related to their life goal to get a handle on their financial barriers and resources.

Peer-run and other programs also are using this workbook all across the country. Some more traditional programs have incorporated "This is Your Life" into their actual intake process. New clients who have difficulty choosing services or life goals use the workbook to help choosing and prepare to act on a goal. Peers are using the workbook on their own, and sharing the results with their providers and supporters. Professional and peer-led education groups complete the workbook together to help members define life goals, while increasing readiness for

change. And special education teachers are using the workbook with students who are considering life after graduation.

I'd be happy to take some questions about these tools or self-determination concepts in general.